

**London South Bank
University**



Great Ormond Street 
Hospital for Children
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Benchmarks for transition from child to adult health services

Research Team

Professor Faith Gibson, Clinical Professor of Children and Young People's Cancer Care, Great Ormond Street Hospital for Children NHS Foundation Trust and London South Bank University.

Susie Aldiss, Researcher in Child Health, London South Bank University.

Dr. Hilary Cass, Paediatric Neurodisability Consultant, Guy's and St Thomas' NHS Foundation Trust and President, Royal College of Paediatrics and Child Health.

Professor Judith Ellis, Chief Executive Officer, Royal College of Paediatrics and Child Health.

Tanya Pettigrew, Service User.

Laura Rose, Adolescent Clinical Nurse Specialist, University College London Hospitals.

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and

- the stakeholders from various professional roles within health and social care including: medical consultants, registrars, clinical nurse specialists, psychologists, occupational therapists and academic researchers.

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For permission requests please contact:

Prof Faith Gibson:

Faith.Gibson@gosh.nhs.uk

Faith.Gibson@lsbu.ac.uk

Contact details

Professor Faith Gibson (Project Lead)

Faith.Gibson@gosh.nhs.uk

Faith.Gibson@lsbu.ac.uk

Susie Aldiss (Researcher)

susiealdiss@lsbu.ac.uk

Study website:

www.transitionstudy.co.uk

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Background

An increasing number of children with long-term health conditions are now surviving into adulthood. Thus, there are an increasing number of children with long-term health needs or complex disabilities who will require on-going specialised care. The provision of health care for this group of young people has been the focus of attention for some time, with a number of reports over the past decade highlighting the need for improvement in this area in order to better meet the needs of young people (e.g. Department of Health, 2006 & 2008; Royal College of Nursing, 2013; Royal College of Physicians of Edinburgh, 2008).

The journey through adolescence to adulthood is a challenging time of physical, psychological and social change. Young people with any form of long-term health condition face even greater challenges having also to deal with important changes in the care they need and the way it is provided. The role of the young person, and also their parents/carers, will change with the young person often wanting and being expected to exercise greater independence in the management of their condition. Health service provision which fails to meet the needs of young people and families at this time of significant change may result in deterioration in health or disengagement with services which can have negative long-term consequences. Thus, the transfer of adolescents from child to adult services is a crucial time in the health of young people who may potentially fall into a poorly managed 'care gap'.

Transition services aim to bridge the 'gap' between child and adult services. 'Transition' can be defined as "a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health care system" (Blum et al, 1993 p.573). Unfortunately, transition by this definition is often not always how young people describe their experience. Numerous research studies have reported that some young people experience the transfer to adult care as disjointed and more of a one-off transfer, rather than a process of preparation that they are involved in (e.g. Kirk et al, 2008; McCann et al, 2014; Shaw et al, 2004; Wray and Maynard, 2008). Such experiences seem to resonate across young people with different diagnoses. A review focusing on the qualitative literature on transition by Fegran et al (2014) described themes relating to experiences of loss of relationships with the child care team combined with insecurity and a feeling of being unprepared for what was ahead.

Lack of 'being prepared' was also a finding from the recent report on transition from the Care Quality Commission (CQC, 2014). Here only 54% of young people described preparation for transition that had enabled them to be involved in the process as much as they wanted to be and 80% of pre-transition case notes reviewed had no transition plans for health (CQC, 2014). There are examples of services where successful transitional care programmes have been implemented (see Crowley et al, 2011) and the CQC (2014) reported that what works well was often associated with specialist services, such as cystic fibrosis and cardiac services, and in essence this consisted of: having consistent staff members who

know about the conditions and young person's history, good communication and good information about what to expect.

The priorities set by the CQC (2014) includes the recommendations that:

1. Commissioners and providers must listen to, involve and learn from young people and their families and understand what they want from their care.
2. Existing good practice guides must be followed to ensure young people are properly supported through transition.
3. GPs should be more involved at an earlier stage, in planning for transition.
4. Adolescence/young adulthood should be recognised across the health service as an important developmental phase.

These benchmarks for transition have been developed with young people, parents and professionals with the aim of improving transitional care for young people and enabling the sharing of best practice between services. As such they offer an example of a 'practice guide' to support transitional care.

Best practice – general indicators

The factors and indicators for these benchmarks focus specifically on transition and the needs, wants and preferences of young people and their parents/carers. However, The Department of Health has published some general indicators for best practice when benchmarking (Department of Health, 2010)¹, which should be considered alongside the factors described in this document. These general indicators have been adapted here to refer specifically to young people and parents:

People's experience

- Young people and parents/carers feel that care is delivered at all times with compassion and empathy in a respectful and non-judgemental way
- The best interests of young people and parents/carers are maintained throughout the assessment, planning, implementation, evaluation and revision of care and development of services
- A system for continuous improvement of quality of care is in place

Diversity and individual needs

- Ethnicity, religion, belief, culture, language, age, gender, physical, sensory, sexual orientation, developmental, mental health, social and environmental needs are taken into account when diagnosing a health or social condition, assessing, planning, implementing, evaluating and revising care and providing equality of access to services

Effectiveness

- The effectiveness of practice and care is continuously monitored and improved as appropriate
- Practice and care are evidence-based, underpinned by research and supported by practice development

¹ Source department of Health (2010) Essence of Care 2010, TSO (The Stationery Office): Contains public sector information licensed under the Open Government Licence v2.0.

<http://www.nationalarchives.gov.uk/doc/open-government-licence/version/2/>

Consent and confidentiality

- Explicit or expressed valid consent is obtained and recorded prior to sharing information or providing treatment or care
- Young people's best interests are maintained where they lack the capacity to make particular decisions
- Confidentiality is maintained by all staff members

People, carer and community members' participation

- Young peoples', parents/carers' and community members' views and choices underpin the development, planning implementation, evaluation and revision of personalised care and services and their input is acted upon
- Strategies are used to involve young people and parents/carers from isolated or hard to reach communities

Leadership

- Effective leadership is in place throughout the organisation

Education and training

- Staff are competent to assess, plan, implement, evaluate and revise care according to all young people's and parents/carers' individual needs
- Education and training are available and accessed to develop the required competencies of all those delivering care
- Young people and parents/carers are provided with the knowledge, skills and support to best manage their care

Documentation

- Care records are clear, maintained according to relevant guidance and subject to appropriate scrutiny
- Evidence-based policies, procedures, protocols and guidelines for care are up-to-date, clear and utilised

Service delivery

- Co-ordinated, consistent and accessible services exist between health and social care organisations that work in partnership with other relevant agencies
- Care is integrated with clear and effective communication between organisations, agencies, staff, young people and parents/carers
- Resources required to deliver care are available

Safety

- Safety and security of young people, parents/carers and staff is maintained at all times

Safeguarding

- Robust, integrated systems are in place to identify and respond to abuse, harm and neglect
- All agencies working with young people and their families take all reasonable measures to ensure that the risks of harm to young people's welfare are minimised.

Use of the benchmarks for transition

Although these benchmarks focus on moving from child to adult health care they could also be applied to other moves between different services such as when young people move from child to adolescent services.

These benchmarks should be used in conjunction with The Department of Health's quality criteria for young people friendly health services, 'You're Welcome', which sets out principles to help commissioners and service providers to improve the suitability of health services for young people <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>.

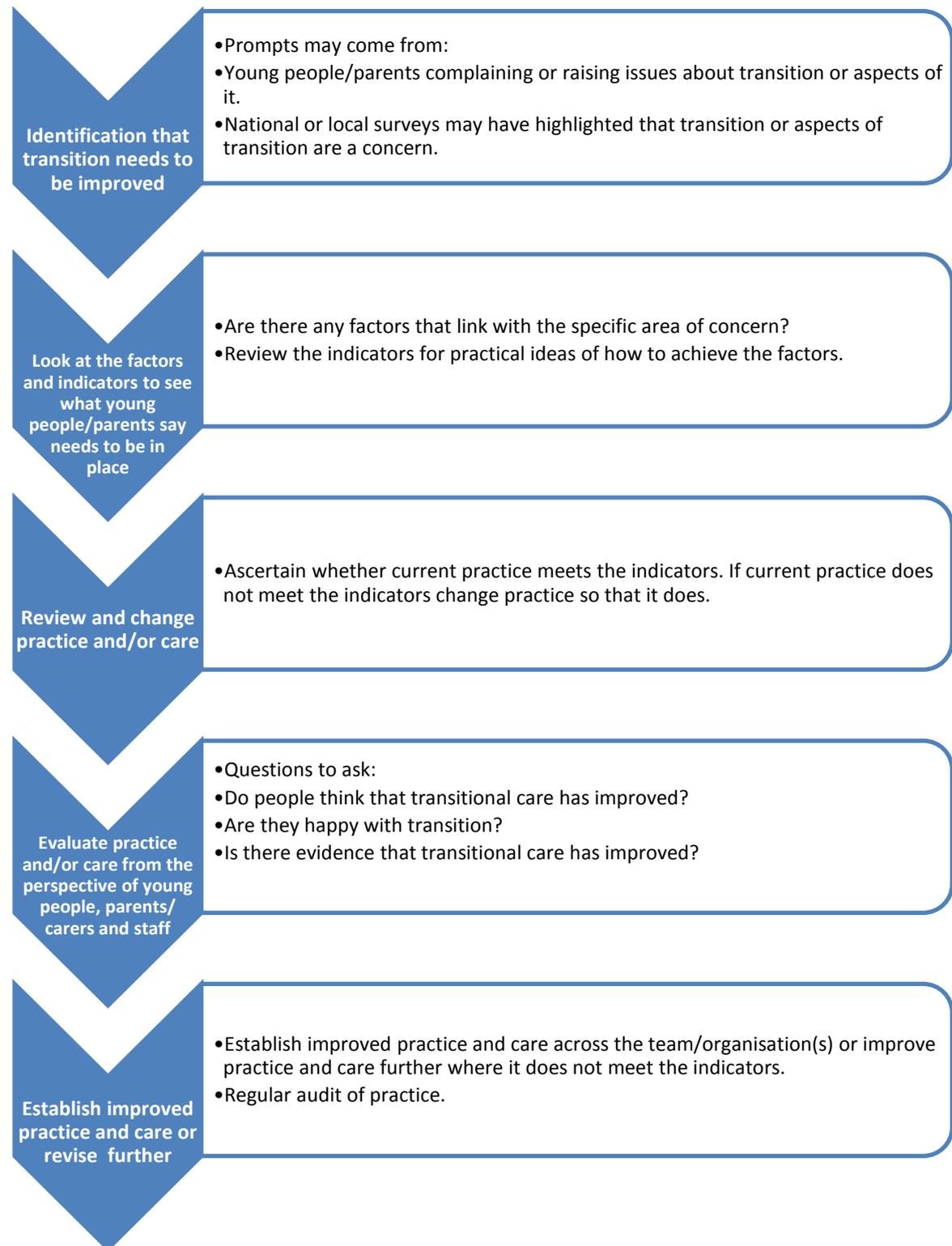
Detailed guidance on the use of benchmarks is available in the 'How to use Essence of Care 2010' document

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216690/dh_119970.pdf. The following 'quick start guide' has been adapted from this document²:

² Source: Department of Health (2010) How to Use Essence of Care 2010. TSO (The Stationery Office): Contains public sector information licensed under the Open Government Licence v2.0.

<http://www.nationalarchives.gov.uk/doc/open-government-licence/version/2/>

Quick start guide for using the Benchmarks for Transition:



Development of the benchmarks for transition

These benchmarks were developed in three stages:

Stage 1: Workshops, focus groups and interviews were held with:

- 21 stakeholders from across the United Kingdom, leading on transition for young people from child to adult health care
- 36 health professionals working with young people locally in the London area (from both child and adult services)
- 13 young people with long-term health conditions and 11 parents.

Two researchers analysed the transcripts and information gathered from these groups and using qualitative content analysis (Morgan, 1993) pulled out a list of factors that were mentioned as being important when young people move from child to adult health care, along with some examples of good care/practice in each area. This list of factors was sent out to young people and parents for them to select the factors they thought should be included in the benchmark. They were also asked to add any additional factors that had been missed along with more examples of good care/practice in each area.

Stage 2: The benchmarks were refined following the comments from young people and parents and then sent out to the same group of young people and parents again to add in statements of best and poor care/practice for each of the factors.

Stage 3: The benchmarks were sent out to all the stakeholders, professionals, young people and parents involved in the study so far for comment and were refined based on the feedback received. This refined document was finally distributed to the professionals, stakeholders and families for final comment.

Benchmarks for transition from child to adult health services

Agreed person-focused outcome

Young people and their parents/carers experience timely and effective transition.

Definitions

For the purpose of these benchmarks:

Transition is:

‘The purposeful, planned movement of adolescent and young adults with long-term physical and medical conditions from child-centred to adult-orientated health care systems’ (adapted from Blum et al, 1993 p570).

Transition is a process, not a one-off event, which starts within child health services and continues in adult services. Within this process, **transfer** occurs, which refers to the point at which the young person moves to adult health services and is discharged from child health services. Transfer does not represent the end of transition, ‘transition is only completed when young people are functioning competently within the adult service’ (McDonagh and Gleeson, 2011, p26).

As it has previously been suggested that the process of preparation for transition should start in early adolescence (Gleeson and Turner, 2012), the term **young people/young person** refers to anyone aged 11 upwards who will be moving from child-based to adult health care.

The term **‘parent(s)’** refers to whoever the young person would identify as their main carer(s) and therefore it is important they are included in the transition process.

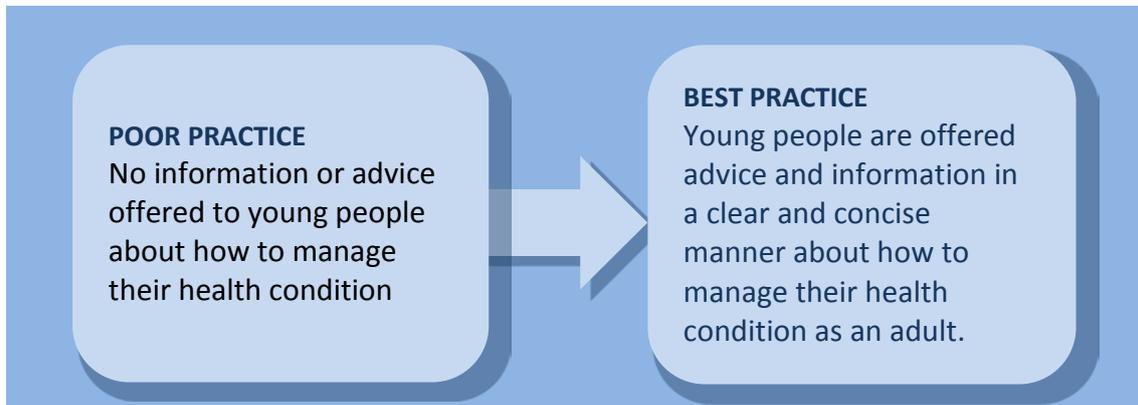
Agreed person-focused outcome

Young people and their parents/carers experience timely and effective transition

Factor	Best practice
Factor 1: Moving to manage a health condition as an adult.	Young people are offered advice and information in a clear and concise manner about how to manage their health condition as an adult.
Factor 2: Support for gradual transition.	The young person as they progress through the transition process is gradually prepared and provided with personally understandable information and support.
Factor 3: Co-ordinated child and adult teams.	The young person is supported through a smooth transition by knowledgeable and coordinated child and adult teams.
Factor 4: Services 'young people friendly'.	Young people are provided with care and in an environment that recognises and respects that they are a 'young person', not a child or adult.
Factor 5: Written documentation.	Concise, consistent and clear written document containing all relevant information about the young person's transition is provided to the teams involved in the transition process.
Factor 6: Parents.	Parents are included in the transition process gradually transferring responsibility for health to the young person.
Factor 7: Assessment of 'readiness'.	The young person's readiness for transition to adult care is assessed.
Factor 8: Involvement of the GP.	The young person's GP is informed of the plan for transition and is able to liaise with other relevant teams to facilitate services requested/needed by the young person.

Factor 1

Moving to manage a health condition as an adult



Indicators of best practice for factor 1

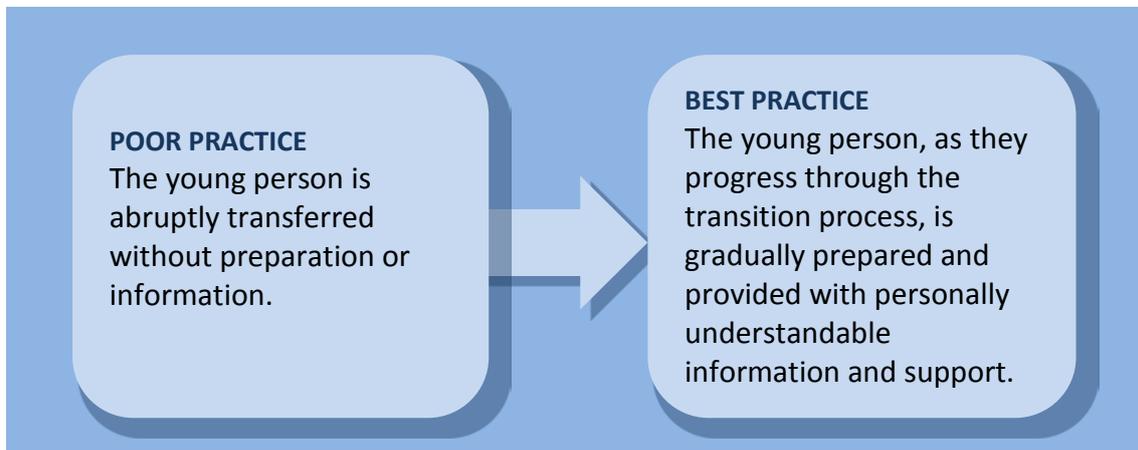
The following indicators support best practice for transition:

- a) Health professionals have good interpersonal and communication skills, good knowledge of the young person's condition and the ability to signpost appropriately.
- b) Ensure the young person understands their health condition (including information about their treatment when they were younger and how it may affect them now and in the future).
- c) Information on life as an adult with their health condition is given in an appropriate format.
- d) Information about their treatments and medications is given in an appropriate format.
- e) Information on how to order, collect prescriptions and book, rearrange and cancel appointments is given in an appropriate format.
- f) 'Lifestyle' advice is given (e.g. about healthy diet, alcohol, smoking, recreational drugs, exercise, sexual health, staying well).
- g) Advice about work/future career or education is given.
- h) Advice about fertility and whether their condition can be passed on genetically is given, if appropriate.
- i) The young person is helped to make decisions about the management of their condition and health at a pace appropriate to their needs.

- j) The young person is helped to gain confidence when talking with health professionals without parent(s) being there.
- k) Information about external support services and charities is offered.
- l) Information on where to go for further advice is given (including contact details for the medical team/consultant/Clinical Nurse Specialist/primary care).
- m) The young person is guided to make the most of peer support.
- n) *Add your local indicators here*

Factor 2

Support for gradual transition



Indicators of best practice for factor 2

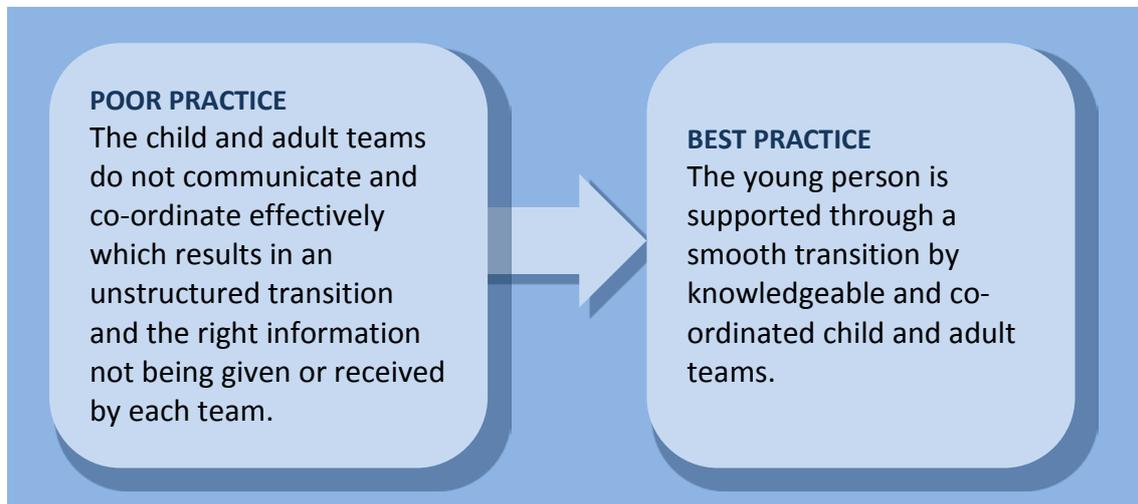
The following indicators support best practice for transition:

- a) Early information about transition and moving to adult care is given to young people and parents with information about what young people/parents can expect. What is expected of each of them throughout the transition process is made clear.
- b) The plan for transition is frequently discussed with young people and parents, decisions are shared and they have clear information about the timeline for transfer and when this will happen.
- c) Health professionals communicate with the young person in a way that is consistent with the young person's stage of development and understanding.
- d) Health professionals take into account what else is happening in a young person's life and avoid transferring them at difficult times (e.g. during major exams, during a period of illness crisis/instability).
- e) The young person and parent(s) know who to contact for transition information.
- f) There is a co-ordinated approach to transition for young people with multiple or complex needs. Co-ordination should extend beyond speciality and organisational boundaries to include all services accessed by the young person.
- g) Young people are introduced to the adult service team and have the chance to visit facilities (including the adult inpatient area if the young person is likely to be admitted).

- h) The transition process is flexible and tailored to the young person's developmental level.
- i) Information about transition is provided through different media (e.g. leaflets, websites).
- j) Young people and parents are given the opportunity to end the long-term relationship with the child care team appropriately.
- k) Transfer to adult services does not represent the end of transition, support for the young person continues after the move to adult care has taken place.
- l) *Add your local indicators here.*

Factor 3

Co-ordinated child and adult teams



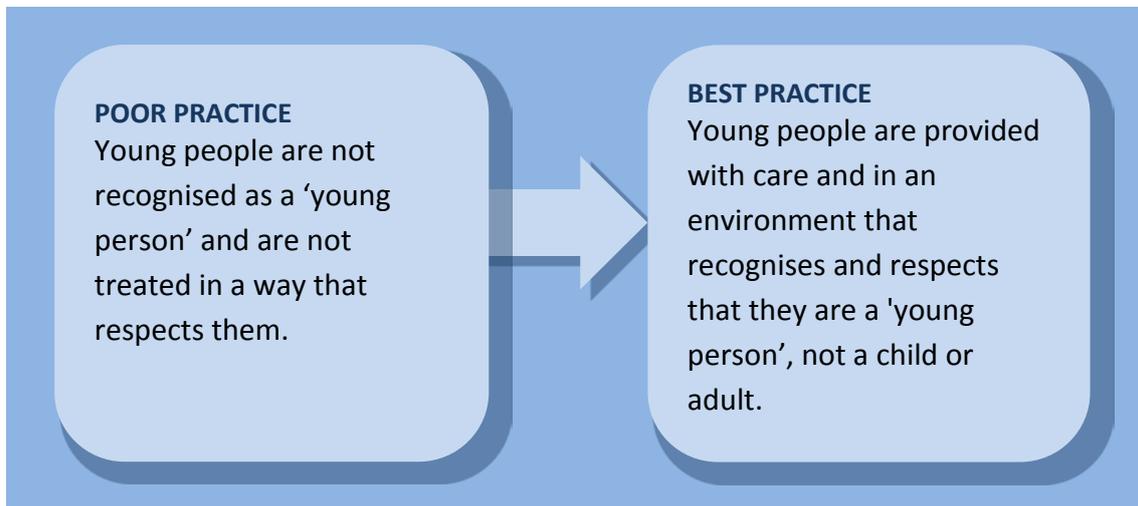
Indicators of best practice for factor 3

The following indicators support best practice for transition:

- a) Health professionals receive effective training about the stages of adolescence, how some long-term conditions may affect development, how to care for young people and how best to communicate.
- b) Training is followed by an assessment to ensure the knowledge, communication skills and competence of health care professionals.
- c) Early communication between the child and adult teams about the plan and policy for transition.
- d) Relevant documentation is passed to the adult team about the young person.
- e) Clear written plan and policy for transition is shared between child and adult teams.
- f) Joint clinics held between the adult and child teams which are young person-centred. Where possible, the joint clinic is held in the adult clinic environment.
- g) The opportunity for someone from children's services to accompany the young person to their first adult appointment is offered.
- h) Contact details for both teams is shared with the young person and parents and the young person and parent are informed about which team to contact and when.
- i) There is a keyworker/clinical nurse specialist co-ordinating care and liaising with the intra and multidisciplinary team.
- j) *Add your local indicators here.*

Factor 4

Services 'young people friendly'



Indicators of best practice for factor 4

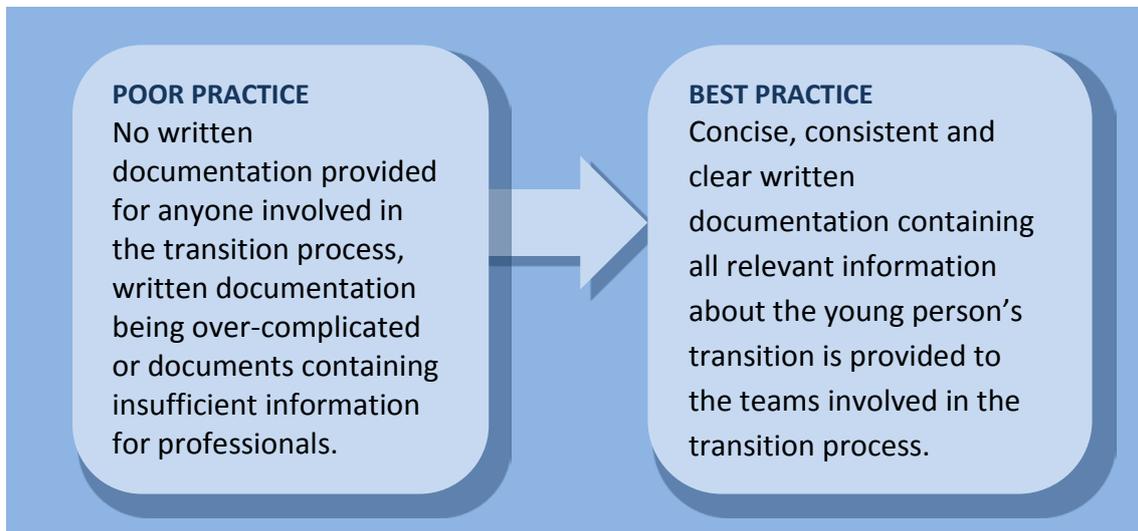
The following indicators support best practice for transition:

- a) Young people are recognised as a 'young person', not a child and not an adult.
- b) Young people are treated with respect.
- c) Information given to young people is open and honest and at a level they can understand.
- d) Information is offered in different formats (e.g. websites, apps, printed materials).
- e) There is opportunity for the young person to talk to health professionals without parents.
- f) Appropriate environment and privacy for young people in clinics is provided.
- g) Appropriate environment and privacy for young people who are inpatients.
- h) Adult inpatient and outpatient services recognise young people may need extra emotional support.
- i) Communication related to the young person is addressed directly to the young person and not 'care of parent/guardian'.
- j) Health professionals are aware of how to care effectively for young people regarding their dignity and that many young people are body conscious and easily embarrassed.

- k) Health professionals are aware of the importance of education and how interruption of education can create stress and anxiety for the young person.
- l) Health professionals are aware of the importance of transition, what 'good transition' looks like and the anxieties young people and parents face during this period.
- m) Good communication and interpersonal skills are essential, if health professionals are unable to communicate well with young people, the young person will be 'turned off'.
- n) Health professionals are approachable, patient and non-judgemental.
- o) *Add your local indicators here.*

Factor 5

Written documentation



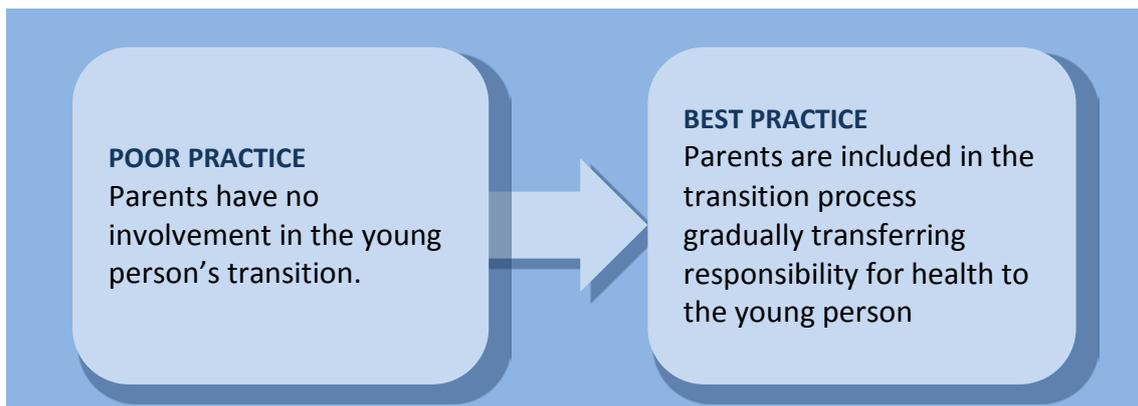
Indicators of best practice for factor 5

The following indicators support best practice for transition:

- a) There is an integrated care pathway with details of the patient journey, specific activities and timeline to be used by the young person, parent/carer and/or key worker.
- b) Young people/parents having to repeat information to health professionals is avoided by the use of written information.
- c) Written plans for transition are used (e.g. health passports/e-documents) which are co-created and completed by the young person and care team.
- d) The written plans are regularly reviewed and updated.
- e) Specific and general written information about transition is provided for young people and parents in a clear and concise way. Examples of the information which could be provided are: a Q and A section, experiences of young people who have moved to adult care, appointment times and contact details for the care teams.
- f) Clear, concise and relevant information about the young person to be provided to the adult team.
- g) *Add your local indicators here.*

Factor 6

Parents



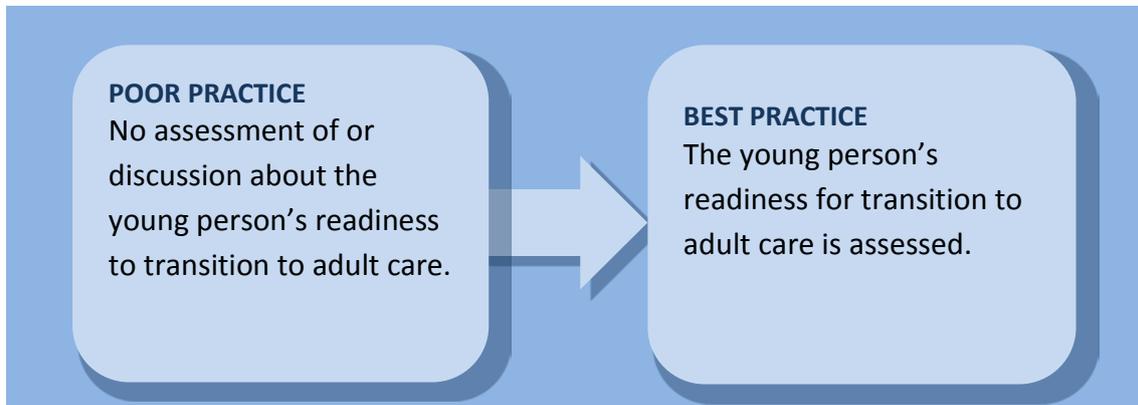
Indicators of best practice for factor 6

The following indicators support best practice for transition:

- a) Help for parents to gradually 'take a step back' but continue to support the young person's self-management.
- b) Opportunities for parents to talk to health professionals without the young person present while maintaining the confidentiality and trust of the young person.
- c) Parents are informed about the plan for transition.
- d) Parents are involved in gradually shifting the responsibility for management of the young person's condition to the young person.
- e) A point of contact is provided for parents to make enquiries/raise concerns.
- f) Parents know that young people will have timely check-ups/reviews and have knowledge of how the adult service is going to work.
- g) Written information is provided for parents to offer advice and tips about gradually 'stepping back' from the young person's care as required.
- h) Parents of young people without capacity to consent are aware of how this will be managed in adult care and that legal parental responsibility ceases at age 18.
- i) *Add your local indicators here.*

Factor 7

Assessment of 'readiness'



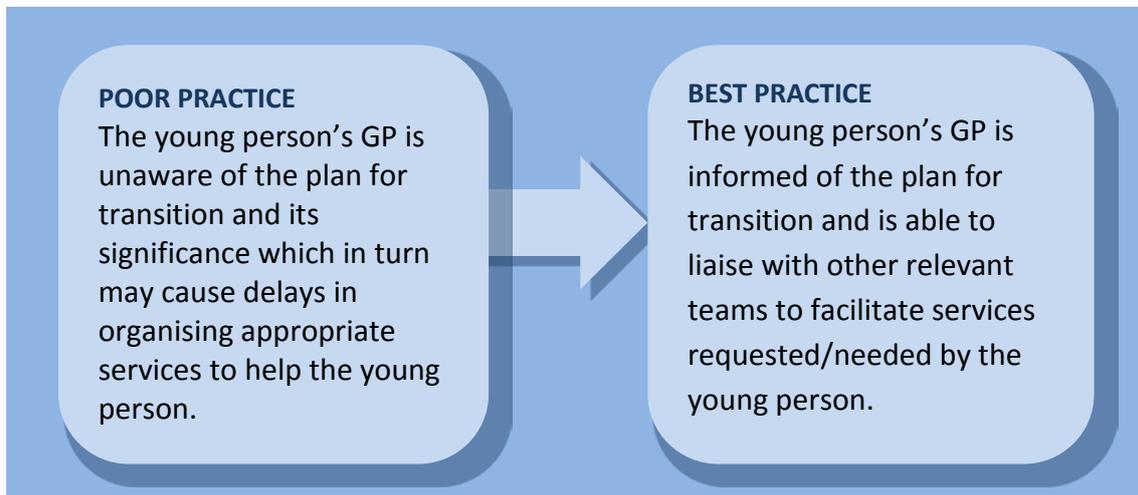
Indicators of best practice for factor 7

The following indicators support best practice for transition:

- a) Readiness for transition is frequently assessed through conversations held during clinic appointments.
- b) Use of a relevant documentation/checklists may be used to assess how ready the young person is to move to adult care (examples available here: <http://www.chimat.org.uk/transitions/prof/checklist>)
- c) All documentation is shared with the young person, so that they can inform and are in charge of their own information.
- d) Parents are asked for their opinion and feedback about whether or not the young person is ready for transition.
- e) Readiness is discussed with the young person and they are helped to develop any gaps in skills, knowledge or confidence needed to manage their health and transition to adult care.
- f) *Add your local indicators here.*

Factor 8

Involvement of the GP.



Indicators of best practice for factor 8

The following indicators support best practice for transition:

- a) The GP is involved in the transition plan.
- b) The GP is the link to further primary care services, such as university/college healthcare team.
- c) The young person can choose to share their transition plan with their GP.
- d) The GP has contact details for the transition team, where one exists.
- e) Young people are encouraged to access primary care to discuss transition and transfer and their role in the young person's ongoing care.
- f) Primary care should be informed if young people are failing to engage with secondary and tertiary care.
- g) *Add your local indicators here.*

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