



Department of
**Health, Social Services
and Public Safety**

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AN ROINN
**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

MÁNNYSTRIE O
**Poustie, Resydènter Heisin
an Fowk Siccar**



Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs

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Introduction

Overview

This pathway guides community services in meeting the needs of families, children and young people, aged up to 18 years, who have complex physical healthcare needs. This is defined as:

Children (and young people) with complex physical healthcare needs are those who require a range of additional support services beyond the type and amount required by children generally and those usually provided to children with impairments and long-term illnesses.

The vision guiding services is:

Children and young people in Northern Ireland who have complex physical healthcare needs will receive co-ordinated, high-quality, child and family-centred services which are based on assessed needs, manage well the risks to life, promote the child and parents' health and well-being, encourage the social inclusion of children and families, and, where possible, enable them and their families to live ordinary lives.

The Pathway has four strands.

Strand U represents the universal community services that will have been involved to some extent in the care of the child either prior to admission to hospital or to whom the child is referred on discharge. However it is the interfaces between these services and the specialist provision described in Strands 1 to 3 that are covered by the ICP. A service framework covering Children's Health and Social Wellbeing is in preparation by the DHSSPS. This will define the detail of this Universal strand. Links with the universal primary care services are contained in Strands 1 to 3 of the Pathway.

Entering the Pathway

It is presumed that the child and family will enter the Integrated Care Pathway from the acute hospital, although this may not always be so. The child's stay in hospital could be of varying lengths of time and may result from a condition that is present from birth or the result of a trauma in later life.

It is possible that the child may be transferred from a Regional Unit to an Area Hospital. The inter-hospital transfer arrangements are not dealt with in this plan. However re-admissions to acute hospitals are covered under Strand 2.

Strand 1: The first strand of the ICP covers the transfer to community services. This is a crucial phase in the life of the child and family and handled successfully will contribute greatly to the family's confidence and their trust in services.

Strand 2: Describes the community services available to the child and family. These would usually cover the chronological age range from birth to the child's 18th birthday. This strand entails a range of provision although not every child and family will need or want all the possible services.

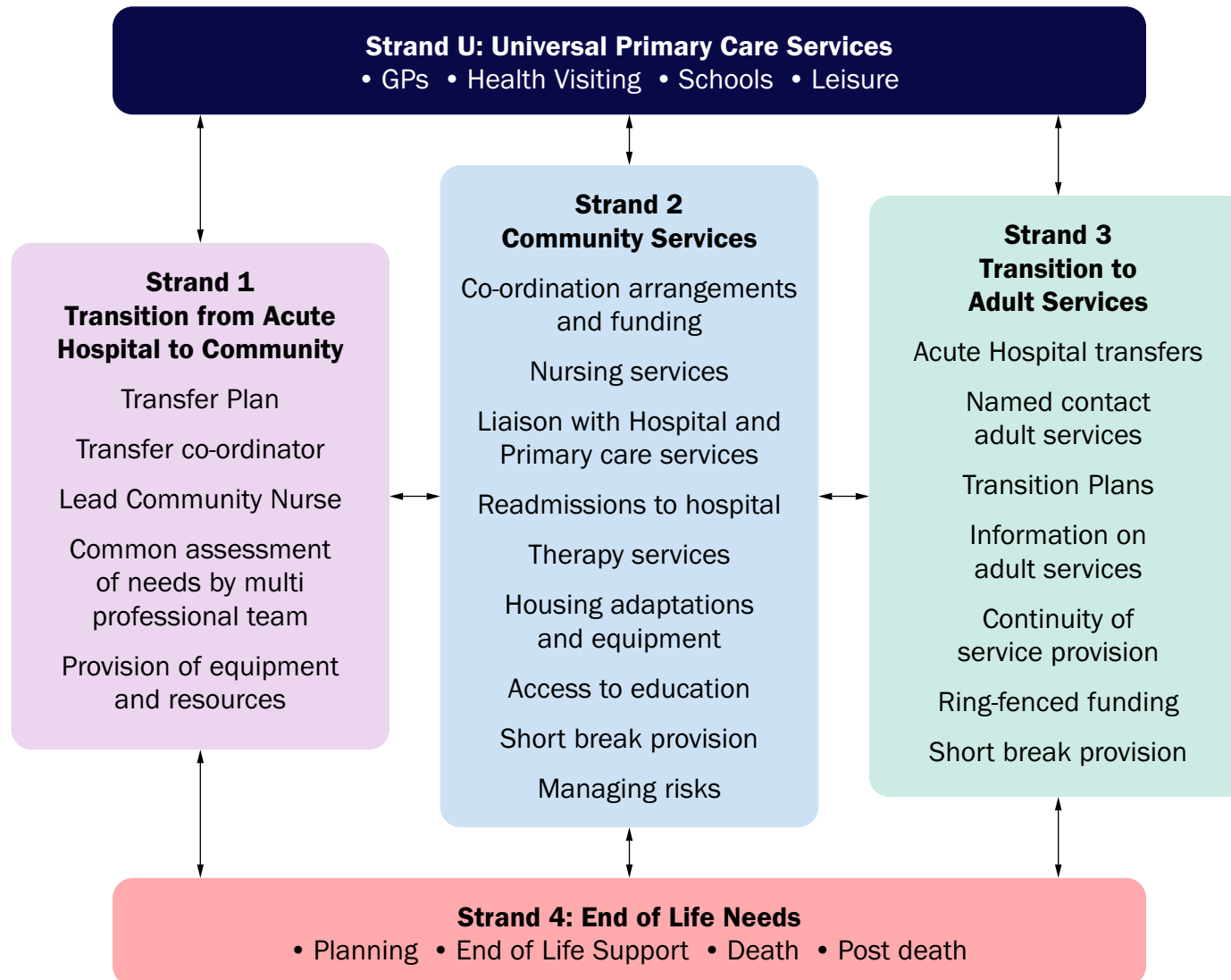
Strand 3: Outlines the transfer arrangements to Adult services. This aspect is the more poorly developed at present; partly because of the relatively few children who have required this strand of the care pathway to date but the numbers will rise in the future as their life expectancy increases. An equivalent Care Pathway for Adult persons would greatly assist the transfer process but this is unavailable at present. HSC Trusts could commence work on such a Pathway based on the model proposed here.

Strand 4: Much of this content of this strand has been taken from the Care Pathway produced by ACT (The Association for Children's Palliative Care: 2004) that covers End of Life and Bereavement. This strand of the pathway could be entered from any of the previous three strands and staff need to be prepared for it.

Introduction

NB The strands are related to one another as the arrows indicate. Actions listed under one strand may have to be commenced under an earlier strand. However for clarity they have been grouped under the strand in which the desired outcomes are listed.

Within the Pathway, a key standard is defined for each Strand and the key outcomes expected. The main actions to be taken by community services are then detailed and a suggested agency or person is assigned responsibility for its implementation. These actions reflect current best practice or actions which are commended in recent reports and research studies. They also embody parental wishes and aspirations. Consideration needs to be given as to how the view of the children and young people are obtained throughout the ICP. The use of Independent Advocacy is a possible option.



Introduction

Recording Actions

The tables of actions within each strand are used to record the services provided to the child and family under each action. Also any deviations from the proposed action should also be noted, such as omissions or improvements that occurred. The reasons for the deviation should be noted.

These records are a crucial tool in sharing information with families and across professionals as well as providing a means of further developing the ICP. In time, it would be possible to specify more explicit criteria regarding service responses, e.g. time limits within a response is made. The Pathway records could then be used for auditing purposes.

In the future, it is hoped to provide the Pathway electronically either for down-loading from an Internet site or as a CD-Rom. This would also assist with updating the content of the ICP or adapting it for localities.

THIS IS THE PATHWAY FOR:

Name of child/family:						
Date of birth:						
Date Pathway started:						
Date of latest update:						

NB. The Regional Assessment Tool to identify Children & Young People with Complex Physical Healthcare should be completed for each child on the Pathway.

Strand 1: Transition from Acute Hospital to
Community Services

Name of Hospital	
Date hospitalised	

Strand 1: Transition from Acute Hospital to Community Services

The key standard for Strand 1 is:

Every child, having been assessed as having complex physical healthcare needs in the hospital setting, should have an agreed transition/discharge plan involving the hospital, community services (both universal and specialist) and the family. The resources required at home should be provided before the child leaves the hospital or as soon as possible thereafter.

Key outcomes – Strand 1

The key outcomes to be accomplished under this strand are:

- Discharge planning should be an integral part of care within the acute hospital setting and commenced from birth or on admission.
- Community services should be notified as soon as practical about the child's admission/transfer/discharge; most likely via the manager of the community children's nursing team.
- A lead community children's nurse should be agreed prior to transition/discharge. It is likely that s/he will act as community care co-ordinator for the family but if not another member of Trust staff should be assigned to take on this role.
- There should be community in-reach to the family in hospital, preferably by a personal visit(s) or via the telephone.

- Planning for the transition/discharge should begin as soon as possible with a multi-disciplinary team meeting and a clear plan devised in agreement with the child, family, hospital and community services.
- Appropriate hospital and community professionals (including the child's GP and health visitor) should be invited to become involved and clear plans should be in place for shared medical care of the child with a community paediatrician and GPs.
- Essential equipment and one month's supplies should be provided to the family/carers before the transfer takes place.
- Competency based training – with underpinning knowledge - should be initiated and overseen by hospital staff and completed for essential carers (including family members) prior to discharge.
- Clear lines of communication should be agreed between the family and community services; family and hospital; hospital and community services.
- A 24 hour contact number(s) should be provided for the family. Ideally this should be of community staff (if available) but otherwise of ward staff in acute hospital.
- A home visit from community nursing staff ideally should take place on the day of discharge or if not possible, a phone call is made followed by a visit the next day.
- The community care co-ordinator will work in partnership with other services to provide a suitable service plan.

Strand 1: Transition from Acute Hospital to Community Services

Record of Actions in Strand 1

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Step-down/transitional protocols from acute care to community services need to be identified in each HSC Trust area. These should also cover discharges from the Royal Belfast Hospital for Sick Children to local acute hospitals as well as to community services.		
Acute	Transition/discharge co-ordinators should be appointed (usually) from nursing staff within each acute hospital. They will liaise across medical consultants and other specialisms, such as allied health professionals and social work.		
HSC Trust	Children who cannot be discharged from hospital due to the lack of community provision should be notified to the relevant commissioning board. HSC Trusts should ensure that they are fulfilling their responsibilities under the Children Order to assess and review children in these circumstances and plan to meet their needs.		
Acute/ Community	Parents need to be informed on the procedures to be followed with respect to obtaining funding from commissioners and the recruitment and selection of any healthcare assistants who may be required.		

Record of Actions in Strand 1 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Acute/ Community	Parents need to be given a clear and realistic indication of the supports that will be available to them on discharge from hospital and the demands likely to be placed on them.		
Acute/ Community	A lead community nurse should be identified for each child referred from hospital who will most likely act as community care co-ordinator ¹ . The lead nurse will liaise with the discharge co-ordinator in the hospital and provide community 'in-reach' to the family.		
Community	A local, named community paediatrician should be identified who will co-ordinate medical care, e.g. with GP.		
Community	A joint assessment of support needs at home and community settings will be undertaken by the hospital staff and the lead community nurse in conjunction with the parents. The lead nurse will involve other community colleagues in this as appropriate – social workers and AHPs – and the voluntary sector. Consideration needs to be given to Understanding the Needs of Children in Northern Ireland (UNOCINI) as the core assessment for children and young people. The specialist Nursing assessment will link with UNOCINI as required, enhancing the information already available.		

¹ See Key Worker standards produced by CCNUK.

<http://www.ccnuuk.org.uk/skins/CCNUK/downloads/keyworker.pdf>

Strand 1: Transition from Acute Hospital to Community Services

Record of Actions in Strand 1 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Community	The lead nurse in conjunction with community colleagues will order the provision of equipment and supplies and ensure their delivery prior to the child's transfer home, subject to the parent's preferences.		
Community	Assessments are undertaken on any housing adaptations that may be required. Arrangements are put in place to facilitate the child's care on an interim basis.		
Community	Pharmacy arrangements are identified including out-of-hours arrangements and procedures for reviewing medication.		
Community	The recruitment and training of healthcare assistants will be undertaken as required. Support staff rotas will be drawn up and provided in advance to the family.		
Community	A 24 hour emergency contact numbers should be provided for the family. This could be within the acute hospital for weekends and night-time. Hospital staff need to be provided with contact numbers of community staff.		

Record of Actions in Strand 1 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Acute/ Community	Nursing teams will train parents in any necessary procedures, using agreed evidence based protocols. These protocols will be available in writing and shared between nursing teams who may be involved with the child.		
Acute	The hospital discharge or transition co-ordinator will maintain contact with the family for a minimum of one month via personal visits or telephone calls. This contact could be maintained for longer if felt appropriate by the co-ordinator and the family.		
Community	The support plan agreed prior to the transfer should be reviewed within two weeks of the child's transfer and thereafter at agreed intervals (see Strand 2). The discharge co-ordinator should be invited to the first review.		
Community	The health visitor and school nurses should be informed of the discharge plans.		
Community	Plans for short breaks are developed in conjunction with parents (see Strand 2 section h).		

Strand 1: Transition from Acute Hospital to Community Services

Comments/Notes on Strand 1

Date	Person making note	Comment/Note

Strand 2: Community Support
Services

Date first discharge from acute hospital (if appropriate):

Strand 2: Community Support Services

The key standard for Strand 2 is:

Every child and family should have a multi-agency support plan agreed with them for the delivery of co-ordinated actions to meet their individual needs. This plan should be regularly reviewed. They should be facilitated to enjoy a good quality of life as a family.

Key outcomes – Strand 2

The key outcomes to be accomplished under Strand 2 are:

- Families will have access to up-to-date, accurate information, in a range of accessible formats, about the range of services and supports available to them in their locality. All professional staff with whom families come in contact, will also have this information.
- Families will be allocated a named contact person who will co-ordinate the supports available to families. This role should be included in the person's job description and protected time allocated for this function.
- Each family will have a named 'core group' of professionals; those who have most contact with the child, such as teacher, therapist, social worker or nurse.
- The support plan will be drawn up in conjunction with families and reflect their aspirations and needs for their child and for the family.

- A holistic and multi-agency approach will be used by community staff to record the outcomes of assessments, reports and reviews, thereby avoiding the need for multiple procedures and record forms. These records, which will include the Assessment of the child's and family's needs, will be held by parents and should accompany the child into different settings/agencies thus avoiding parents having to repeat information. (NB This may require a change to existing professional practice around record keeping.)
- The core group including the named contact will meet with parents as required to review service plans but at a minimum of every six months. Copies of these plans will be made available to families and all relevant service personnel. Parents will be able to request a review at any time. These reviews could be done in conjunction with other required reviews, such as Looked After Children reviews.
- Strategies for managing risks will be developed in conjunction with family carers and shared with all relevant personnel and agencies. These should balance safety with opportunities of ordinary living and be regularly reviewed.
- The children will have timely access to hospital and GP appointments.
- The necessary adaptations, equipment and supplies are available to families on a timely and reliable basis.
- The child has access to educational and leisure activities.
- Carers will be informed of their right to have an assessment undertaken of their needs as a carer.
- Carers will be informed about Direct Payments and assisted in making a decision about the appropriateness to them.
- Opportunities are provided for parents to have a break from caring.
- The emotional well-being of parents and siblings, and their quality of life is a major focus of reviews and the provision of advice and support.

Strand 2: Community Support Services

Record of Actions in Strand 2 (NB In this Strand, the actions are grouped into nine sub-strands).

A) KEY ACTIONS – Co-ordination of services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Each family should be allocated a staff member who will act as the main point of contact for the family and the co-ordinator of service inputs. The goal is to provide a co-ordinated approach to support and care. The co-ordinator will be the professional who has most ongoing contact with families and will introduce them to other relevant services and act as a conduit of information for other services. Community children’s nurses may continue to fulfil this role (this may need to be made more explicit than at present).The person could also be from voluntary/statutory provision if more suited to role.		
HSC Trust	There may be scope to combine the role of co-ordinator with some of the functions of care manager as in Adult Services. For example, there would be advantages in co-ordinators having access to budgets that can be used to provide emergency short break or augmented home supports on a short-term basis. This funding could be channelled through nursing budgets as bank/relief staffing.		

A. Key actions – Co-ordination of services cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	An up-to-date, electronic directory of services and supports should be prepared for each HSC area with contact details of personnel. Copies or print-outs of this should be given to all families and be made widely available to all professionals with whom families are likely to come into contact.		
Community co-ordinator	Families are given the contact details of local support groups for parents and of young people's advocacy groups.		
Community co-ordinator	A 'service map' should be created for each individual child and family and shared with all services and persons who have an involvement with them. Names and contact details should be provided of all those professionals and agencies included in the map.		
Community co-ordinator	Opportunities should be provided for wider family members such as grandparents to be involved in training and planning for the child, e.g. through family-group, case conference.		
HSC Trust Managers/ HSC Board	Annual audits are undertaken of the ICP records to identify improvements to services and their co-ordination. Summary reports should be sent to the Regional HSC Board for onward referral to DHSSPS.		

Strand 2: Community Support Services

Comments/Notes on Co-ordination of Services:

Date	Person making note	Comment/Note

B. Key actions – Nursing and other personal support services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Each child/family should be allocated to one nursing team who co-ordinates all inputs from nursing services in the community. (Presently a variety of nurses may be involved with the one child and family.) This nurse will liaise with the family health visitor.		
HSC Trust	A funded out-of-hours, on-call service (e.g. up to 10.00 pm) by community nurses for children with complex physical health needs should be provided throughout Northern Ireland. HSC Trusts should assess whether it is required in their area.		
Community Nursing/Acute	Opportunities should be made available to nurses within acute and community settings (e.g. CNLD, district nurses) to develop additional knowledge and competencies in working with children who have complex physical health needs, and in supporting their families.		
Community Nursing/Acute	All nurses should be inducted and mentored in the provision of nursing services to the children to whom they have been allocated, including relief and bank staff. A robust training plan needs to be in place involving acute hospital staff if appropriate. Evidence-based practice should be followed, e.g. contained in relevant care pathways for the particular condition if available ² .		

² The Contact a Family organisation has a useful directory of rare conditions that can assist practitioners in accessing information in a family-friendly format.

<http://www.cafamily.org.uk/about.html>

Strand 2: Community Support Services

Comments/Notes on Nursing and other personal support services

Date	Person making note	Comment/Note

C. Key actions – Access to Hospital and Community Clinics

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Hospital clinics should synchronise their appointment systems as far as possible, so that families make a minimum number of visits to hospitals/clinics. For example, when multiple appointments are required, these are offered for the same day. Personal Identifiers should make this easier to achieve.		
HSC Trust	Transport pick-ups in rural areas to take children to hospitals should be appropriately timed.		
HSC Trust	Systems are in place to ensure that children and young people who find it hard to wait, do not have to stay unduly at outpatient clinics, general practice surgeries or child development centres. Where appropriate, double booking times or first/last appointment times are available for disabled children.		
HSC Trust	Privacy is ensured when staff are obtaining confidential information about the child and family or when they convey news that may be distressing to families.		

Strand 2: Community Support Services

C. Key actions – Access to Hospital and Community Clinics

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust Schools	Facilities for giving personal care in privacy are available in all locations in health, social care and education services that are used by families with a child who has personal/health care needs.		
HSC Trust	Access to hospital services is regularly audited and improved, in partnership with disabled children and their parents.		

Comments/Note on Access to Hospital and Community Clinics:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

D. Key actions – Readmissions to Hospital

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Children and young people with complex physical health care needs who are prone to health crises should have open access to paediatric wards where they are known for assessment/admission (if beds are available), or they are seen urgently on request in A&E departments and GP practices; e.g. a 'Fast Track' card should be given to these families (e.g. Craigavon Area Hospital use these cards).		
HSC Trust	A standardized record of all the child's care needs is prepared that can be given to the hospital staff on admission.		
Ambulance Service	Ambulance control should maintain a record of the child and the hospital to which he/she should be taken in an emergency.		
Community staff	Contact is maintained between community staff and the child/family, e.g. through healthcare assistants working with the child in the hospital and giving parents a break.		

Comments/Notes on Readmissions to Hospital:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

E. Key actions – Access to therapy services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Therapeutic interventions are agreed and overseen by appropriately trained paediatric therapists.		
Therapists	Parents or carers, children and young people are active partners in decisions about rehabilitation or therapy services, with agreed goals for what it is intended to achieve and how they can help.		
Therapist	Therapy is delivered in the most appropriate setting, which may include the home if this suits the child or young person; or where children and young people attend educational settings it is offered within that setting, and strategies are developed with teachers who support the child's full learning experience. Otherwise therapy appointments are offered outside of school hours to ensure a minimum absence from school.		
Therapists	Protocols are agreed for the delivery of interventions by teachers and learning assistants.		

E. Key actions – Access to therapy services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
AHP Managers	<p>Reviews are undertaken of local therapy services in order to:</p> <ul style="list-style-type: none"> a) Promote self-referral, simplifying the care pathway, and reduce excessive waits that may affect a child's development; b) Improve administrative systems and processes for referral and discharge, and the effectiveness of outcomes of different therapeutic regimes, such as group sessions, and c) Ensure that the supply of timely therapy services is sufficient and resourced to meet the needs of children and young people who require it, based on assessed needs. This will involve increased capacity to ensure that all children and young people attending early education settings and mainstream or special schools have equal access to therapy. 		

Strand 2: Community Support Services

Notes on access to specific therapeutic services

Therapy service – additional action steps	Details of Action taken with dates	Reasons for deviation

Comments/Notes on Access to therapy services:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

F. Key actions – Access to Housing adaptations and Equipment

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Consideration of housing, community equipment and wheelchair needs is included in the overall planning of community services for children and their families. Multi-agency partnerships are in place to facilitate this.		
HSC Trust	Equipment and assistive technology is tailored to the individual needs of the child and their future development. (NB These should not be means-tested.) These should be provided on a timely basis.		
HSC Trust	Parents and other carers are given training and support in the use of the equipment and assistive technology, including who to contact in an emergency and out-of-hours.		
HSC Trust/ Partner agencies	The children are able to use/access the equipment and assistive technology they need in all places they typically spend time (e.g. school, home, short-term care settings, and leisure settings).		
HSC Trust	Deliveries of bulky health equipment and supplies are sufficiently frequent so that families are not required to store large amounts in the family home. Local emergency stocks of health equipment/supplies are obtainable 24 hours a day.		

Comments/Notes on Access to Housing adaptations and Equipment:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

G. Key actions – Access to Education

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	The child's co-ordinator (or CCN) is involved in planning educational placements and in the statementing process. Any necessary equipment should be available in school.		
Named contact HSC Trust	The child's class teacher and/or support assistant, along with the school nurse if there is one, should be considered members of the core team of professionals and should be involved in the development and review of a common support plan for the child and family.		
Community Nursing/ Schools	Written protocols around transporting the children to/from school and for dealing with medical emergencies should be developed by community health personnel and school staff. Induction training is provided in their use.		
HSC Trust	HSC Trusts and Education need to work in partnership with regards to training and supervision of Additional Special Classroom support who provide care to the child while in the school setting.		
Named contact HSC Trust	Funding arrangements are in place to provide additional support to the family during school holidays or when the child is at home for periods of time due to illness etc.		

Comments/Notes on Access to Education:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

H. Key actions – Short break Provision

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Social Worker	An assessment is undertaken of the child/young person's need for short breaks and their preferences for the form these take.		
Social Worker	An assessment of Carer's needs is undertaken and regularly reviewed. This should include the need for short breaks. Negotiation may be required to reconcile the wishes of young people and family carers.		
Social Worker	Families are informed about Direct Payments and how they can be used to provide breaks from caring.		
HSC Trust	Families should be informed of all the short break options offered by statutory and voluntary agencies. A choice of short breaks should be offered to families, including domiciliary support in the family home, or the child being looked after outside the family home.		
HSC Trust	Consideration should be given to the formal use of wider family members (who are competent to care for the child) in the provision of short break care for which they would receive payment.		

H. Key actions – Short break Provision

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Staff working in existing or planned short break services should receive training in the care for children with complex physical healthcare needs and ongoing support from nursing and AHPs involved with the child.		
HSC Trust	Young people and parents of children with conditions from which they are likely to die before adulthood should be provided with information on the NI Children’s Hospice and the services it provides. The decision to avail of such services should be through choice of the child/young person and parents.		
HSC Trust	The nominated social worker convenes regular LAC reviews of children in receipt of care outside of the family home. These meeting should provide an opportunity to review the short break needs of families.		

Strand 2: Community Support Services

Comments/Notes on Short break Provision :

Date	Person making note	Comment/Note

I. Key actions on managing risk

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Service providers	All services contributing to the child's care will regularly assess the risks to the child and to others in the context of their service. Risk management plans will be developed, agreed with the child (where appropriate) and with their parents and the outcomes included in the care plan. These plans will be shared with all agencies.		
Nursing team	The nursing assessment tool, developed for assessing complex physical healthcare needs, acts as one vehicle for the multi-professional identification of risks associated with the child's health care needs.		
Nursing team	For all risks identified within the nursing assessment tool, child-specific risk management protocols should be established and implemented. These will be shared with family and all personnel in all services involved in the support and care of the child.		
Nursing team	An environmental risk assessment is undertaken and completed as part of the discharge planning process from hospital and regularly reviewed.		

Strand 2: Community Support Services

I. Key actions on managing risk cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Multidisciplinary team	At multidisciplinary discharge planning meetings, risks over and above health related risks should be identified, and risk management strategies implemented that are specific to the child and family.		
Multidisciplinary team	Risk management arrangements should be reviewed at regular intervals as part of any review.		

NB *The Dignity of Risk* handbook published by the Shared Care Network has been devised and developed jointly by the Council for Disabled Children and Shared Care Network. It gives an overview of Health and Safety issues incorporating a rights based approach, includes the latest information on key areas of risk and provides guidelines and examples of good practice. Price: £30.00 (inc. p&p) ISBN 1-904787-22-3 (2004)

See also Jeanne Carlin's (2005) book '*Including me: Managing complex health needs in schools and early years setting*'. London: Council for Disabled Children.

Comments/Notes on managing risk

Date	Person making note	Comment/Note

Strand 3: Managing transitions to
Adult Service

Planned Date of Transfer	
---------------------------------	--

Strand 3: Managing transitions to Adult Service

The key standard for Strand 3 is:

Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services, and no loss of needed service should be experienced as a result of the transfer.

Key outcomes – Strand 3

The key outcomes to be accomplished under Strand 3 are:

- Planning for the transfer should commence around the young person's 14th birthday or earlier as required. Families need support and reassurance as they prepare for change and as they work through it.
- A 'transitional care nurse' is appointed in community services to assist with the preparation for change.
- Adult services in acute and community settings should be notified at this time about the pending transfer and appropriate staff invited to attend futures planning meetings.
- In the acute sector, a hand-over meeting should take place between the two medical specialists – children and adult - the young person and the family. Ideally one lead consultant will be named if there are two or more consultants involved with the child. Likewise a transitional care nurse from the children's ward will be identified to liaise with adult wards.

- The young person and family will be given the opportunity to familiarise themselves with the adult ward and nursing staff.
- Ideally one named contact will be identified from adult services in the community.
- The named contact for the young person and family from children's services will convene a futures planning group for the young person which will include representatives from adult services – such as therapy, social work, day centre as anticipated. Prior to the transfer, they will meet at least annually to review the transition plan.
- The group from HSC will liaise with their counterparts in education to co-ordinate transition planning. One common Transition Plan will be prepared.
- Clear lines of communication should be agreed between the family and adult community services; family and hospital; hospital and adult community services.
- HSC Trusts will anticipate the budgets that are required to provide continuity of service provision for assessed needs when the young person transfers from Children to Adult Services. The families will not be wait-listed for services that they continue to need.

Strand 3: Managing transitions to Adult Service

Record of Actions in Strand 3

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Acute Hospitals	Within acute hospitals, a common age of transfer is introduced across medical specialisms for the transfer of children with complex physical healthcare needs to adult services, preferably around 18 years of age.		
Acute Hospitals	<p>Within acute hospitals, procedures should be put in place to plan for the transfer of children with complex physical health needs to adult medical and nursing services. This could include:</p> <ul style="list-style-type: none"> • A named transition nurse from the Children’s ward. • A hand-over meeting taking place between the consultant doctors, the young person and the family. • A visit to the adult ward to which the young person would be admitted. 		
HSC Trusts	In community services, a transitional care nurse is appointed to co-ordinate the transfers from children to adult services. S/he will act as the main point for other team members in each service.		

Record of Actions in Strand 3 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Named contact	The family's named contact in children's services will be responsible for convening the transition planning meetings with the young person and family, and for maintaining contact with transition planning within education.		
Adult services HSC Trusts	An accessible information leaflet should be made available to young people and families that details the adult service options and contact persons.		
HSC Trusts	If possible there should be continuity of service provision into the adult years, such as healthcare assistants within home, family placement providers, direct payments. This will require adult services to budget in advance for these needs.		
HSC Trusts	Likewise the costs of nursing, therapy, short breaks and other provision needs to be budgeted in advance within adult service budgets.		
Adult services	Appropriate short breaks should be planned by adult services well in advance of the person requiring them.		

Strand 3: Managing transitions to Adult Service

Comments/Notes on Strand 3

Date	Person making note	Comment/Note

Strand 4: End of Life Needs

Strand 4: End of Life Needs

The key standard for Strand 4 is:

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.

Key outcomes – Strand 4

The key outcomes to be accomplished under Strand 4 are:

- Children and families should be supported in their choices and goals for quality of life to the end.
- Professionals should be open and honest with families when the approach to the end of life is recognised.
- Joint planning with families and relevant professionals should take place as soon as possible.
- A written plan of care should be agreed including decisions about methods of resuscitation. The Emergency services should be informed. Care plans should be reviewed and altered to take account of changes.

- There should be 24-hour access to pain and symptom control including access to medication. Those managing the control of symptoms should be suitably qualified and experienced.
- Short break options with medical and nursing input will be available to family carers.
- Emotional and spiritual support should be available to the child and the carers.
- Parents should feel in control of events after death and should be enabled to make their own choices, e.g. care of the body and funeral arrangements.

- The needs of siblings and grandparents should be considered and included at the time of death and afterwards.
- Bereavement support should be offered for as long as the family needs.

NB: *The content for this Strand is largely taken from the Care Pathway produced by ACT (2004). Further suggestions are welcome.*

Strand 4: End of Life Needs

Record of Actions in Strand 4

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Core Team	A plan for end of life care should be documented with the family and young person. This will include their needs and wishes. This may have to be done urgently if the child condition deteriorates rapidly but at other times it can be done in advance once a terminal phase is recognised or in response to a family's expressed concerns.		
HSC Staff	A <i>small</i> core team of key professionals will be identified to support the family and child. These persons will be selected from those with an involvement with the child and family (in statutory and voluntary services). The team needs to be open and honest with the family about the probability that the child's life is nearing an end.		
HSC Trusts	Someone on the team or known to the team (e.g. palliative care nurse) has the specialised skills and knowledge to support the family in approaching the discussion of death and opening the possibility to the child or young person in order that they contribute actively to the plans.		

Record of Actions in Strand 4 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trusts	The plan will cover a Personal Resuscitation Plan that outlines the emergency treatment to be used, e.g. by ambulance crews and local A&E Departments. Options around organ donation should be explored and explanations given about post mortems. Parental and child decisions around these issues should be respected.		
HSC Trusts	Written information should be provided to the family about the procedures and entitlements following death; to include registering the death; procedures required for cremation, use of funeral directors who are members of accredited bodies, advice on benefits and entitlements.		
HSC Trusts	The family and the young person will be enabled to choose the environments in which end-of-life care is provided. In Hospice or Hospital settings, family members should have 24 hour access.		
HSC Trusts	The family and team will have 24 hour access to paediatric palliative care specialists and other qualified nursing staff and paediatricians so that symptoms and pain can be controlled* and unnecessary admissions to hospital avoided.		

* Royal College of Nursing. *The Recognition and Assessment of Acute Pain in Children: Implementation Guide*. London: RCN, 2001.

Strand 4: End of Life Needs

Record of Actions in Strand 4 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Core Team	Decisions around the removal of life prolonging treatments must be taken in full consultation with the child (if appropriate) and the family and the time provided for them to come to a decision.		
Core Team	Around the time of death, the child and family will be given the necessary privacy and space. Professionals should be sensitive to their needs and take their cue from them. The family's cultural and religious beliefs should be respected. The questions and concerns of siblings should be addressed.		
Named Contact	All those professionally involved with the child should be informed about the death. The named contact may do this on the family's behalf if they wish it. This includes the GP, social worker, school, AHPs, short break service and hospital staff. It is important that any department or service expecting future contact with the child are informed so that further letters are not sent out.		

Record of Actions in Strand 4 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Core Team	Members of the core team should maintain contact with the family to offer co-ordinated bereavement support through the agency best suited to their needs. Particular care of siblings is needed. Assistance with dealing with secondary losses could be provided, such as loss of friendships, financial hardships, physical ill-health.		
HSC Trusts	Professionals who have been closely involved with the care of the dying child and family will have access to emotional and psychological support.		

Strand 4: End of Life Needs

Comments/Notes on Strand 4

Date	Person making note	Comment/Note

Useful References

Royal College of Nursing. (2001) *The Recognition and Assessment of Acute Pain in Children: Implementation Guide*. London: RCN.

Royal College of Paediatrics and Child Health. (1997) *Withholding or withdrawing life saving treatment in children: a framework for practice*. London: RCPCH.

Talbot, K. (2002) *What forever means after the death of a child*. London: Brunner-Routledge.

NB The Children's Palliative Care Reflective Model of Supervision can be a useful tool for supporting all those professionals involved with the care of the dying child.

Notes

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