



Long Term Ventilation Care for Babies, Children and Young People:

London Quality and Safety Standards

Contents

Introduction	3
Governance.....	3
Key terms	4
1. Transition to adult services	5
2. Formal Reviews of Care Plan and Continuing Care Assessment (if applicable)	5
3. Agreement of Care (Level 2/3 only)	6
4. Involving Children, Young People and Families	7
5. Staffing Levels.....	7
6. Competence Framework and Training Plan	9
7. Personal health budgets	9
8. 24/7 Children's Nursing Support (Level 2/3 only)	10
9. Observation of Practice	11
10. Monthly contact (Level 2/3 only)	12
11. Education of Children and Young People on Long-Term Ventilation (applicable for levels 1/2/3).....	12
12. Emotional Support for Staff	13
13. Home equipment	13
14. Clinical Supervision	13
15. Administrative and Clerical Support.....	14
16. Equipment Responsibilities	14
17. Data Collection	14
18. Review and Learning	15
19. Document Control.....	15
ANNEX A: Key worker definition	17
ANNEX B: LTV education standards.....	18
ANNEX C: Examples of delegated tasks.....	21

Introduction

Long-term ventilation (LTV) refers to various types of respiratory support provided every day for a period of at least three months. Ventilation is delivered either via a tracheostomy tube (invasive) or via a face mask or nasal cannula (non-invasive). The aim of LTV is to improve survival and quality of life in people with conditions that have led to respiratory failure (NCEPOD 2020).

For this group of babies, children and young people (BCYP), usually referred to as 'long-term ventilated children's', the last three decades have seen a move from life in an intensive care unit, to life at home and in the community. The health complexity of BCYP is an evolving picture as technology and medical interventions advance. For a growing group of BCYP, the need for ventilation remains when the acute stage has passed. Ventilation is also now sometimes initiated electively in sleep units or ward environments. It is also recognised that as children grow and develop with these complex needs, support for their medical condition will be required in a number of settings including education.

These Quality Standards apply to the care of LTV BCYP at all levels of need and cover those requiring both non-invasive ventilation and invasive ventilation (via a tracheostomy).

The following standards are based on the "Midlands Children's Long-Term Ventilation Network (and Partners in Paediatric) Quality Standards: Services providing Long-Term Ventilation for Children and Young People" (October 2022)^{1,2} (MCLTVN) with adaptations made in collaboration with clinical experts, ICB quality leads, commissioners and community providers, in order to meet the needs of LTV BCYP and health and care professionals commissioning and providing care within the London region.

Governance

These standards aim to identify best practice and improve the quality of services for BCYP needing LTV based on national guidance and evidence. It is for organisations to adopt these standards in their local governance processes.

¹ For access to the full standards document – you can request a copy [here](#).

² The West Midlands standards are consistent with NHS England's Service Specification E07/S/c 'Paediatric Long-Term Ventilation'. They are based on and support implementation of national strategies and guidance, including NICE guidance and Quality Standards.

The Quality Standards for services providing LTV for BCYP should sit within organisations' overall clinical governance arrangements. The MCLTVN Quality Standards describe the clinical governance arrangements which should be in place.

Compliance in NHS provider organisations will usually be assured through other regulatory bodies. Non-NHS organisations may wish to use the MCLTVN Quality Standards to assure themselves of the robustness of their overall clinical governance arrangements.

Key terms

BCYP: Babies, children and young people. In this document, 'child' is used to include infants, children and adolescents.

LTV: Long-term ventilation

MCLTVN: Midlands Children's Long-Term Ventilation Network

Continuing Care Service: As recognised in the National Framework for Children and Young People (2016) a continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. This service supports the ongoing care of the child or young person at home and in the community by providing a home care package. Continuing Care may be provided by a range of different types of organisations including NHS Trusts, voluntary sector and private providers.

Levels of need: Within this group of children there are different levels of need, as defined in the National Framework for Children and Young People's Continuing Care (2010):

- **High (Level 1):** Is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm.
- **Severe (Level 2):** Requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection but would be unwell and may require hospital support.
- **Priority (Level 3):** This includes those with no respiratory drive at all who are always dependent on ventilation, including those with no respiratory drive when asleep or unconscious who require ventilation and one-to-one support while asleep as disconnection would be fatal.

Responsible parent /carer: An individual who has parental responsibility for the child or young person, or who is the child's primary informal carer, and who is responsible for making day-to-day decisions about their care and welfare. This may include a parent, legal guardian, foster carer, or another person with delegated parental responsibility, in accordance with the Children Act 1989.

Commissioned trained adult: An adult who is employed or commissioned by the NHS or a commissioned care provider or employed under a personal health budget, to deliver elements of a child or young person's continuing care package, and who has received appropriate training and competency assessment to meet the child's identified healthcare needs. This excludes parents or unpaid family carers unless they are separately commissioned and trained as part of the care package.

Note: The use of numbered levels in this document should not be confused with the levels in the nomenclature of Paediatric Critical Care units.

1. Transition to adult services

Planning for transition to adult services should start at around 14 years (where appropriate due to prognosis) and transition normally takes place between the ages of 16 and 18. In exceptional circumstances transition may be delayed but should be completed by the age of 25. Flexibility in the age of transition may be necessary to reflect the individual needs of each young person and/or while commissioners and providers ensure appropriate arrangements are in place.^{3,4,5}

Some services provide care for adults as well as children and so transition will involve a change of funding arrangements at the age of 18 but may not require a change of care provider.

2. Formal Reviews of Care Plan and Continuing Care Assessment (if applicable)

Each child should have a formal review of their care as required by their continuing care assessment team (if applicable) and at least annually and if there are any changes to the condition of the child and changes are made to their care plan. This review should involve, at least:

- a. The child and their family
- b. Their 'key worker', * Community Children's Nurse, Tertiary Children's LTV Service consultant, community pediatrician, allied healthcare professionals, home care provider, social care and education representatives
- c. Any other staff with regular input to the care of the child
- d. Any other consultants with regular input on the care of the child

The review should cover all aspects of the Personal Care Plan. The child and their family should be offered any relevant additional information, and their Personal Care Plan should be updated. The outcome of the review should be communicated to the

³ The National Confidential Enquiry into Patient Outcome and Death. 'The Inbetweeners' 2023. London

⁴ NICE Transition from children to adults' services, QS 140, 2023

⁵ Office for Health Improvement and Disparities. 'You're Welcome: establishing youth-friendly health care services; 2023.

relevant commissioner of care and to the child's general practitioner. This should be met once for each child (not once in each service).

Notes:

- Reviews of the continuing care assessment and care package should also be undertaken at three months after the child is first discharged from hospital on long-term ventilation.
- Annual reviews should either be undertaken at a single meeting or there should be a robust system of recording and communicating each aspect of the review to all involved in the care of the young person.
- Participation in the review meeting may be by telephone or video link.
- Social care and education representatives' involvement in reviews will depend on the child or young person's needs and age.
- There may be less frequently scheduled reviews of BCYP that fall under level 1/High need, whilst recognising the need for a review in the event of a change in clinical condition.

3. Agreement of Care (Level 2/3 only)

An 'Agreement of Care' between the family and the Continuing Care Service provider should be negotiated and agreed covering the family and service's responsibilities and arrangements for staff while working within the family home (this document may have other names, such as the 'Family Service Agreement'). This should include considerations around cultural needs and require appropriate risk assessments which must be completed as part of the wider care and support planning. This should include identification of an appropriate adult to act in loco-parentis in the absence of the responsible parent or carer, in order to support the commissioned trained adult in the event of an emergency. This support may be identified by the family, or require support from social care partners, as part of a parent carer needs assessment, as set out in section 97 The Children and Family Act.

The implementation of a continuing care package is to support the identified health needs of the BCYP, assessed in collaboration with social care partners and to support the wider family in their caring responsibilities. The support of a commissioned trained adult in the home does not replace the parental responsibilities of the responsible parent /carer. The Agreement of Care / family agreement should include details on:

- How the responsible parent /carer will be supported in a scenario when they need to leave the home environment - a commissioned trained adult cannot be left alone with the young person in case of an emergency.
- Details around how provision will be provided for a second person to remain in the home with the commissioned trained adult, should the responsible parent /carer need to leave as with a babysitting scenario. The responsible parent /carer may have an identified and appropriately trained friend or family member who would be present as a second person (and in loco parentis role) in case of an emergency or social care will need to consider this provision to allow a short break arrangement.

4. Involving Children, Young People and Families

The service should have:

- a. Mechanisms for receiving feedback from children, young people and their families about the treatment and care they receive – examples of this may include monthly quality call checks with families and identified on call support via duty desks. Best practice is that these are conducted collaboratively with health and social care partners.
- b. Mechanisms for involving children, young people and families in decisions about the organisation of the service
- c. Examples of changes made as a result of feedback and involvement of children, young people and their families

Note: The arrangements for receiving feedback from children, young people and families may involve surveys, including the national patient survey, focus groups and/or other arrangements. They may involve Trust-wide arrangements so long as issues relating to the specific service can be identified.

5. Staffing Levels

The Continuing Care commissioner care support service should have sufficient staff with appropriate competences for the usual number of BCYP cared for by the service, their dependency and the complexity of their needs.

Staffing should include:

- a. Registered nursing staff, of whom a minimum should be 75% children's trained nurses – to provide clinical supervision to the trained adults

- b. Commissioned trained adults, all of whom should have a RQF level 3 qualification in a child or young adult-related subject (or equivalent)

Staffing should be sufficient to meet Standards relating to Observation of Practice (standard 9) and 24/7 Children's Nursing Support* (standard 8).

Cover for absences should be available so that the functions of the service can continue during times of annual leave, study leave and short-term sickness.

Notes:

- Staff may include volunteers with appropriate competences or others paid for by personal budgets.
- If the service also provides care for adults, then 75% of nursing staff caring for children and young people should be children's trained nurses.
- A minimum of 80% of registered nurses being children's trained nurses is desirable, and services should be working towards this level.
- Cover for absences may be achieved through agreed arrangements with another service.

When a complex young person is clinically fit and preparing for discharge from hospital, the nurse assessor will assess the clinical need within the assessment process and work with families and the commissioned provider, to ensure the correct level of clinical care is in place to support within the community.

There are only limited circumstances in which registered nurse input is required in the community. In most cases, care and support can be delivered safely by commissioned trained adults (carers), with clinical oversight provided by registered nurses through a provider-led model.

Commissioned trained adults are trained across varying tiers to deliver many complex care and support tasks in the community. However, there are exceptions where a registered nurse may still be necessary, for example, to manage intravenous access.

As with responsible parents or primary carers, commissioned trained adults receive appropriate training to carry out delegated clinical tasks safely in the community.

A trained nurse will train the continuing care team (commissioned trained adults), review care plans and continue to provide ongoing assessment of clinical competency and continuous clinical supervision for the commissioned trained adults.

It is important for commissioners to be aware of [working directives](#) which inform maximum working hours for staff, and to recognise the potential risks of fatigue and of [exploitation of care workers](#). This includes consideration of commissioned trained adults

who may be working across multiple providers, where cumulative working hours and workload may not be visible to a single organisation, but may nevertheless impact staff wellbeing, safety, and quality of care.

6. Competence Framework and Training Plan

Anyone with caring responsibilities for BCYP on long-term ventilation should have, and should maintain, competencies appropriate to their role.

A competence framework should show the competences expected for distinct roles within the service and how competences will be assessed.

Best practice is to utilise the Pan Thames Paediatric LTV/NIV competencies [Tr-LTV&NIV - Pan Thames Paediatric Long Term Ventilation Network](#). These are regularly reviewed and updated to reflect safe clinical practice. These should be used as the default competency framework, where an alternative is used, this should be clearly identified and the rationale for its use documented.

A training plan for commissioned trained adults and responsible parent/carers, overseen by a registered nurse, should cover achievement and maintenance of these competences. This should be applicable to nuances in settings whereby care is delivered, including home and education settings.

In Annex B “LTV Education Standards”, further guidance has been provided outlining the expected level of LTV skills, competencies, sign-off and skills updates.

Annex C has an example list of delegated tasks, which will vary according to level of patient need.

This standard is additional to the mandatory competences of everyone working with BCYP, such as infection control, information governance, moving and handling, Control of Substances Hazardous to Health and caring for children with disabilities.

7. Personal health budgets

A young person and their family have a right to have a personal health budget and would then employ commissioned trained adults directly. Parents/carers and a core group of commissioned trained adults will receive the initial competency sign-off prior to discharge home. It is recognised that this training may need to continue for some carers once the BCYP returns home facilitated by the clinical nurse manager. They will also have the responsibility as employers, to ensure this is completed annually, as a minimum, for parents/carer employed commissioned trained adults. The annual reviews

for Children and Young People's continuing care should actively seek assurance and a system for formal documentation for oversight purposes.

Any training costs should be factored into the indicative budget set. The nurse assessor involved in the assessment process will be able to support in identifying quality training for the parents/carers to engage in, according to the clinical needs of the BCYP.

8. 24/7 Children's Nursing Support (Level 2/3 only)

A registered children's nurse with competence in the care of children needing LTV should always be available (24/7).

[NMC delegation and accountability](#) provides a reference on delegation of tasks and accountability for registered nurses.

This nurse should:

- Have access to each child's latest Personal Care Plan, escalation plan and other relevant assessments and plans.
- Have information about the equipment used and maintenance arrangements.
- Have access to the child's Tertiary Children's LTV Service for advice.

24/7 Children's Nursing Support should be organised to give reasonable continuity of care. Staff providing this service should have direct contact with BCYP and family four weekly, face to face, either through providing direct care or through observation of the practice of staff providing care if a care package is in place. During this time, commissioned trained adults will be supported and documentation may be reviewed and updated in the home folder or electronic care record, as applicable.

Staff, child / young person and family feedback is important to build relationships, and this should be undertaken monthly.

Notes:

- 24/7 Children's Nursing Support may be provided by the service itself or may be separately commissioned. This may be achieved through collaboration with other services.
- The 24/7 Children's Nursing Support will also require contact numbers for staff, contact numbers for all families, current ventilation prescriptions and Emergency Health Care Plans, current competences for each commissioned trained adult for each child, adverse weather policy, safeguarding escalation pathways, risk assessments and incident reporting processes.

9. Observation of Practice

All children's trained adults should have their clinical skills supervised by a Registered Healthcare Professional.

As a minimum this should include:

- Training support for competency sign-off, including initial 1:1 shadow shift (usually up to 10) with a clinical nurse to allow the commissioned trained adult to:
 - observe the clinical skills required in the care plan.
 - learn the nuances in recognising when a BCYP may need intervention or be deteriorating.
 - learn when to ask for support.

The amount of support will be determined by the clinical nurse delegating the tasks.

- Ideally the training should start in simulation prior to direct work with BCYP.
- 1:1 supervision should be initiated prior to hospital discharge, where appropriate, and be conducted in all settings such as at home and education settings.
- Post competencies sign off - clinical 1:1 supervision 4-6 weekly in home and education settings as appropriate.
- Face to face group training - six monthly including simulation to include troubleshooting, basic life support, and tracheostomy changes *

Risk assessments should be completed for all care environments and clear escalation plans must be in place for the commissioned trained adults to follow in case of an emergency.

Commissioners should be assured that commissioned providers provide safe and quality on call support (24/7) and that commissioned trained adults are familiar with the on-call policy.

In addition, observation of practice in the setting where care is delivered should take place annually, as part of staff competency reassessment undertaken by a Registered Healthcare Professional. The commissioned provider may wish to visit the settings outside of these scheduled times as required.

Note: The purpose of observation of practice is to ensure staff providing care are maintaining appropriate competences and behavior, and abide by the service's guidelines, policies and procedures. The trained adults employing organisation is responsible for ensuring action is taken to address any issues identified during

observation of practice. Records of observation should be maintained by the commissioned trained adult's employing organisation.

10. Monthly contact (Level 2/3 only)

A registered health care professional with competence in the care of children needing long-term ventilation, with responsibility for a package of care, should contact the child and family monthly to monitor their well-being and the adequacy of care arrangements. There should be reasonable continuity of staff undertaking monthly contact.

Notes:

- The monthly contact may be combined with Observation of Practice (above).
- The monthly contact may be undertaken by the 'key worker' or by another member of staff who communicates with the 'key worker' and nominated Community Children's Nurse.
- This does not apply to children needing level 1 care.

11. Education of Children and Young People on Long-Term Ventilation (applicable for levels 1/2/3)

Agreements with Local Education Authorities should be in place covering responsibilities and arrangements for ensuring BCYP with continuing care needs have timely and robust support to fulfil their educational potential, in particular:

- i. Arrangements for liaison with early years settings, schools, and colleges
- ii. Agreement for an Education Health Care Plan for each child
- iii. Visits to the education setting by relevant staff to discuss the care of each BCYP starting LTV.
- iv. Responsibilities of education staff in the care of the child and consideration around care teams supported by CYPCC
- v. Training and assessment of competences of education staff in these responsibilities.

Best practice would include:

- All staff in the education setting and transport services have Basic life support and safety awareness training from a trained professional to support in the event of escalation and an emergency.
- This would constitute as training on what to do to support the main trained adult in the event of an emergency such as in the event of an unplanned

tracheostomy change or seizure management. Staff would not hold overall responsibility but are trained in how to support if there was an emergency.

- vi. Disposal of clinical waste (if applicable)
- vii. Transport to and from the education setting as recognised in the [The Department for Education guidance on home-to-school travel and transport for children of compulsory school age, \(Jan 2024\)](#) primarily the section on Children with medical needs. This guidance outlines local authorities' responsibilities.

Note: Agreements vary and each Local Education Authority may have different support arrangements in place.

12. Emotional Support for Staff

All commissioned trained adults should have direct access to emotional and psychological support or counselling; to include access to debrief and reflective practice.

Notes:

- This also applies to administrative and clerical staff.
- Access to psychological support through occupational health services should be available but is not sufficient for compliance.

13. Home equipment

Where a care package is in place then the following should be available for staff working in the home:

- a. Call system e.g. personal/work mobile phone, doorbell or call system to parents/carers, or an installed alert system where required.
- b. Adequate seating for care staff
- c. Adequate lighting, ideally dimmable background lighting

14. Clinical Supervision

All healthcare professionals should be offered regular clinical supervision appropriate to their role at least quarterly, though this may be required more regularly depending upon

the commissioned trained adult's experience and case complexity. This should include both safeguarding supervision and child/ young person specific supervision.

15. Administrative and Clerical Support

Administrative, clerical and data collection support should be appropriate for the number of children cared for by the service.

Note: The amount of administrative, clerical and data collection support is not defined. Clinical staff should not, however, be spending unreasonable amounts of time which could be used for clinical work on administrative tasks and data entry.

16. Equipment Responsibilities

The Continuing Care provider should maintain a register of equipment, maintenance and servicing arrangements for each child and inform families if any action needs to be taken. This register should be available to 24/7 Children's Nursing Support and Tertiary LTV Advice Service.

17. Data Collection

Commissioners should ensure safe and supportive assurance processes are in place with providers.

As a minimum providers should produce monthly reports detailing:

- Number of children cared for by the service.
- Proportion of face-to-face contact time provided by registered health care professionals*
- names of trained staff on package*
- dates of training and competencies,
- any unfilled shifts and contingency offer including any subcontracting details.
- any issues that may have occurred during commissioned care with narrative around how these are being managed.

In addition, Commissioners should ensure they conduct quarterly contract meetings with providers which should include social care staff where there are joint packages of care, which include monitoring of:

- Number of staff involved in each care package*

*Asterisked sections apply only to BCYP needing level 2/3 care

- Percentage of shifts not covered* (excluding shifts cancelled by parents or due to admission of children to hospital)
- Achievement of monthly contacts*
- Frequency of observation of practice for all children commissioned trained adults*
- Calls to the 24/7 Children's Nursing Support outside normal working hours*
- Achievement of expected timescales for discharge and if there were any delays due to delays in assessment completion or inability to staff the care package.
- Other key performance indicators agreed by the National Service Specification* or Children's Long-Term Ventilation Network

Any reports should be shared with social care partners to ensure all professionals are kept updated.

18. Review and Learning

The service should have appropriate multi-disciplinary arrangements for reviewing and implementing learning from, positive feedback and Learning from Excellence, complaints, outcomes, safeguarding, incidents and 'near misses', along with staff debriefs, peer reviews and benchmarking.

19. Document Control

All policies, procedures and guidelines should comply with Trust or employing organisation's document control procedures.

*Asterisked sections apply only to BCYP needing level 2/3 care

ANNEX A: Key worker definition.

A key worker should have responsibility for:

- a. Maintaining regular contact with the child and their family and providing information, support and advice.
- b. Liaison with the child's named Community Children's Nurse (if a different person)
- c. Keeping relevant documentation up to date, including the Personal Care Plan, Agreement of Care, Education Health Care Plan, Escalation Plan, and related risk assessments.
- d. Identifying who is responsible for the management of equipment and associated consumables.
- e. Informing other services involved with the child about changes to their condition or plan of care.
- f. Informing the child's education system of changes to their condition or plan of care.
- g. Initiating a multi-disciplinary care planning meeting to review the child's plan of care if this is needed before the next planned review date.
- h. Initiating and / or participating in multi-disciplinary discharge planning.
- i. Initiating and updating the child's Common Assessment Framework (if applicable)
- j. Consideration of and acting on safeguarding issues.

This should be met once for each child (not once in each service).

Notes:

- Coordinating and maintaining an overview of the patient's care pathway is central to the key working function. The individual will not be expected to answer all queries and will 'signpost' or support patients and commissioned trained adults in accessing other services or advice. The 'key worker' may or may not be the main provider of health care. They should be available during office hours and cover for absences should be available. The 'key working' functions may be conducted by a small number of individuals rather than a single person, so long as there is good coordination between them.
- This is not applicable to children needing level 1 care only.

ANNEX B: LTV education standards

LTV Education Standards for Procurement of Care Providers:

1. Commissioned trained adult should have training and competence in specific skills required by a child with medical complexity such as LTV, enteral feeding etc. by a registered professional (nurse, physio, doctor etc.) e.g. Educator within the Care Provider
2. Commissioned trained adults should have clinical skills signed off on an appropriate competency framework such as the Paediatric Pan London LTV (PPLTV) Group Parent/ Carer Competency documents for LTV available here: [Tr-LTV& NIV - Pan Thames Paediatric Long Term Ventilation Network](#). As commissioned trained adults are not registered with a professional body, the LTV competencies should be signed for each individual that they are caring for. These LTV skills are non-transferrable unless a registered professional e.g. Nurse Educator from Care Provider assesses that the commissioned trained adult has the skills, delegates the care under the [NMC delegation guidance](#) and updates the commissioned trained adults on the child's specific medical background.
3. Initial commissioned trained adult training (for the initial discharge home) should be provided by the discharging hospital and care provider jointly prior to discharge. The care provider is responsible for signing off each commissioned trained adult as competent using recommended competencies e.g. Paediatric Pan London LTV (PPLTV) Group Parent/ Carer Competency documents for LTV available here: [Tr-LTV& NIV - Pan Thames Paediatric Long Term Ventilation Network](#). The discharging hospitals education responsibility is only for any patient specific training required. The Care Provider is responsible for general skills and competency sign off.
4. Nurses employed by a Care Provider should be able to demonstrate nursing/ HCP competency completion. As written competencies for certain skills such as LTV and tracheostomy have not always been in place, a pragmatic approach should be taken to those nurses deemed to have existing competence without the supporting competency document. Lack of a competency document should not impact on care of a BCYP that is already being undertaken. Ideally a competency document should be completed ASAP by demonstrating the skills to an assessor (a senior staff member who has clinical experience and competency in line with local policy as well as having experience in supervision and assessment e.g., Care Provider Educator). Nurses should demonstrate attendance at an LTV specific update annually e.g. an NHS Network study day/ NHS trust study day/ completion of approved e-learning package or approved private training provider/ Company

clinical representative e.g. ventilator rep. This should include annual updates of specific complex equipment such as the Ventilator, suction machine, nebuliser machine, feed pump, etc. This may be through self-directed online video learning, Care Provider Educator or Company education sessions.

5. Effective suctioning (previously known as deep suctioning, where a suction catheter is passed via the nose or mouth into the back of the throat and further to remove secretions) is a skilled task that can be delegated to other staff provided that the appropriate education, training, sign-off and safety measures are in place to align with the RCN & NMC delegation guidance and the Association of Paediatric Chartered Physiotherapists guidance on Supporting Children's Community Respiratory Physiotherapy Services. The trainer should have the appropriate knowledge to teach this skill (the trainer does not have to be a physiotherapist) and the training may be from the hospital team on discharge or by care providers directly. The care provider is responsible for competency sign off.
6. Both nurses and commissioned trained adults employed by a Care Provider should have annual clinical supervision in practice by a registered professional with relevant skills (e.g. LTV) and competencies e.g. Care Provider Educator
7. The training of commissioned trained adults prior to discharge home should consist of three elements:
 - a. General baseline education regarding the BCYP medical background and diagnosis (e.g., LTV), including teaching on escalation of care and teaching on specific complex equipment such as the Ventilator, suction machine, nebuliser machine, feed pump, etc. This may be through approved online video learning/ e-learning packages, approved general study days e.g., LTV Study Days provided by the NHS Networks and/ or via the Care Provider Educator or Company education sessions.
 - b. Patient specific training provided by/ advised by the Tertiary LTV Centre. This may be provided remotely via virtual presentations or in person and may either be directly to the Paid Care team or to the Care Provider Educator to disseminate further.
 - c. Shadow shifts with the BCYP to meet the BCYP and their family, understand their daily routine, their personal preferences and communication methods if non-verbal. There should be at least one shadow shift completed during the day and one during the night to ensure the commissioned trained adult has experience of BCYP in both an awake and asleep state regardless of if they will be doing night shifts or day shifts when the BCYP is at home. A pragmatic approach

should be taken and a plan devised in conjunction with the clinical hospital-based team particularly if the BCYP has an increased risk from infection or is in a Tertiary Hospital far from their home address (it may then be difficult for commissioned trained adults to attend the hospital to complete the shifts).

- d. Commissioned trained adults should have the basic knowledge and skills (e.g. have attended some general teaching and practiced skills relating to the care of BCYP e.g. LTV knowledge & skills to a good level on a manikin with the care provider Educator) **prior** to arriving for the shadow shifts.

Any ongoing commissioned trained adult training should be provided in the community by the care provider, e.g. for newly commissioned trained adults to the package following discharge home or for an annual update.

- 8 If changing from nurses to commissioned trained adults, this should be clearly documented in writing and clearly communicated to the MDT and family before discharge. Provided there has been no change to the BCYP's clinical status since the decision to change from nurses to commissioned trained adults, once discharged home and appropriate, commissioned trained adults should have shadow shifts with the nurses currently providing the care, with a transition plan over an agreed period e.g. 6 weeks. This should be reviewed prior to the full transition over to commissioned trained adults and extra time for further shadow shifts/ commissioned trained adult training provided if required. BCYP and their family should be fully informed and included in this process.
- 9 Care providers caring for children with medical complexity should have an Educator (with professional registration e.g. nurse) employed within the care agency to provide education, updates and clinical oversight of nurses and commissioned trained adults employed by the care provider. The Educator should have appropriate competencies signed and an annual update of clinical skills from either an NHS network/Trust run external study day or approved private training provider. It is, however, recognised that written competencies for certain skills such as LTV and tracheostomy have not always been in place, therefore the Educator may not have completed these competencies themselves. Until such a time, a pragmatic approach should be applied. The Educator should undertake annual clinical supervision/ teaching peer review. Approved private companies can be utilised for commissioned trained adult training and updates.
- 10 **Private companies** providing LTV education/ training should have a registered professional delivering the training (nurse, physio, doctor etc.) who has completed relevant competencies relating to the training that they are delivering. They should keep themselves current and clinically updated annually (attend relevant study days, conferences etc.) and have annual clinical supervision from

another registered professional with appropriate experience. They should also ideally be CPD accredited with indemnity insurance.

ANNEX C: Examples of delegated tasks.

Competencies will vary according to the individual patient's needs, but delegated tasks will typically include:

- a. Ventilation (including mask/ interface placement for Non-Invasive Ventilation (NIV))
- b. Basic Life Support, including paediatric tracheostomy resuscitation (this is particularly vital as trained adults may not have undertaken emergency care procedures since their initial competency sign off)
- c. Transporting ventilated children.
- d. Professional boundaries
- e. Child and adult safeguarding
- f. Working in the home environment (where applicable) *
- g. Infection control and disposal of clinical waste
- h. Use of relevant medical devices

Where appropriate for the needs of the child:

- i. Paediatric tracheostomy care
- j. Oxygen administration
- k. Humidification*
- l. Nebulisation
- m. Oxygen saturation monitoring
- n. Transcutaneous carbon dioxide monitoring*
- o. Postural care
- p. Respiratory physiotherapy management including use of equipment.
- q. Tracheostomy valve (speaking valve)
- r. Suction of natural and artificial airways
- s. other child/ young person specific healthcare needs (for example, Urinary catheterisation, Spinal care*, Enteral/ oral feeding, tissue viability and Neuro-physiotherapy management including techniques and use of equipment)

Long-Term Ventilation (LTV) Quality and safety standards for Babies, Children & Young People – Clinical Checklist

Comprehensive checklist mapped to the London Quality & Safety Standards (Governance, Clinical Practice, Training, Data & Review).

Date:
Name:
Provider:

Governance and document control

- ☐ Adhere to local clinical governance processes, incorporate London LTV Standards into Trust governance.
- ☐ Ensure all LTV policies, SOPs and guidelines comply with document control requirements (versioning, review dates, owners).
- ☐ Confirm non-NHS providers have equivalent governance; obtain assurance where applicable.

Transition to adult services

- ☐ Start transition planning around age 14 where appropriate; align with prognosis and young person's goals.
- ☐ Plan transfer typically between ages 16–18; if delayed, complete by 25 with documented rationale and plan.
- ☐ Agree adult provider(s), funding flows post-18, handover timeline, named coordinators in adult services.

Formal reviews of care plans and continuing care assessment

- ☐ Hold an annual MDT review as minimum; convene sooner if any clinical or contextual change.
- ☐ Participants include family, key worker*, Community Children's Nurse, Tertiary LTV consultant, community pediatrician, AHPs, home care provider, social care and education (as required).
- ☐ Update the Personal Care Plan; share outcomes with GP and commissioners; record agreed actions and deadlines.
- ☐ Post-discharge: complete a 3-month review for children newly discharged on LTV.
- ☐ Enable participation virtually if required; maintain robust records when elements are completed separately.

Agreement of care (level2/3)

- ☐ Ensure a signed Agreement of Care (Family Service Agreement) sets out family and provider responsibilities and cultural considerations.
- ☐ Complete and file risk assessments (home, education, transport, emergencies).
- ☐ Identify an appropriate adult to act in loco parentis when the responsible parent/carer is absent; document arrangements for a second person present with commissioned staff.
- ☐ Clarify that commissioned trained adults support identified health needs and do not replace parental responsibilities.

Involving children, young people, and families

- ☐ Maintain mechanisms for regular feedback (e.g., monthly quality check-ins, duty desk).
- ☐ Demonstrate changes made because of feedback, share learning with partners.
- ☐ Evidence co-production in service design and individual care planning.

Staffing levels

- ☐ Maintain sufficient capacity based on caseload complexity and dependency levels.
- ☐ Ensure ≥75% of registered nurses caring for children are children trained (aim for 80%).
- ☐ Ensure commissioned trained adults hold RQF Level 3 (or equivalent).
- ☐ Provide cover for leave/sickness so core functions (observation of practice; 24/7 support*) continue.
- ☐ Risk-assess working hours across multiple employers, monitor fatigue risks and wellbeing.

Competencies and training plan

- ☐ Adopt the Pan Thames Paediatric LTV/NIV competencies as default (or record and justify an alternative).
- ☐ Maintain an education plan covering achievement & maintenance of competencies for commissioned adults and parents/carers, overseen by a registered nurse.
- ☐ Follow Annex B expectations: tiered skills, sign-off, simulation, annual updates, and device-specific updates (ventilator, suction, nebuliser, feed pump).
- ☐ Keep clear records of competency sign-off per child; non-transferable unless reassessed and redelegated by a registered professional.

Personal health budgets

- ☐ Offer/confirm Right to Have a PHB; support families choosing to employ staff directly.

- ☐ Plan and fund training within the PHB; assure annual competency updates for PHB-employed staff.

Nursing support

- ☐ Provide 24/7 access to a registered children's nurse competent in LTV; ensure continuity across on-call Rota.
- ☐ Ensure access to current Personal Care Plan, ventilation prescription, escalation/EHCP, equipment and maintenance details.
- ☐ Maintain four-weekly face-to-face contact (direct care or observation of practice) and monthly contact/feedback with family.
- ☐ Ensure contact details, adverse weather policy, safeguarding pathway, risk registers, and incident reporting processes are available.

Observations of practice

- ☐ Provide initial 1:1 shadow shift (typically up to 10) to learn skills, nuances of deterioration and escalation.
- ☐ Initiate 1:1 supervision pre-discharge where appropriate across home and education settings.
- ☐ Post sign-off: schedule clinical 1:1 supervision every 4–6 weeks; deliver six-monthly face-to-face group training including simulation, BLS and tracheostomy changes*.
- ☐ Complete annual observation of practice in the care setting for competency reassessment; retain records and actions.

Monthly contact (level 2/3)

- ☐ Undertake monthly contact by a competent HCP to check wellbeing and adequacy of arrangements; maintain continuity of staff.
- ☐ Combine with observation of practice where practical; document outcomes and share with key workers/CCN.

Education of BCYP on LTV (levels 1/2/3)

- ☐ Agree roles with Local Education Authorities: liaison, EHCP accuracy, pre-placement visits, responsibilities of education staff and care teams.
- ☐ Provide training and competency assessment for education staff involved; include transport arrangements and clinical waste disposal where relevant.

- ☐ Provide BLS and safety-awareness training to all education/transport staff to support escalation in emergencies.

Emotional support for staff

- ☐ Ensure access to psychological support/counselling, debrief and reflective practice for all staff (including admin/clerical).

Home equipment and environment

- ☐ Confirm call/alert systems available (e.g., phone, bell, installed system as required).
- ☐ Provide adequate seating and suitable, ideally dimmable, lighting for care delivery.

Clinical supervision

- ☐ Provide regular clinical supervision at least quarterly (more frequently by complexity/experience).
- ☐ Include safeguarding supervision and child-specific supervision.

Administrative and clerical support

- ☐ Ensure appropriate administrative, clerical and data support proportional to caseload; avoid excessive admin burden on clinicians.

Equipment responsibilities

- ☐ Maintain a register of equipment per child with servicing/maintenance schedules; share with 24/7 support and tertiary advice service.
- ☐ Inform families promptly of any actions required regarding equipment.

Provider monthly reports

- ☐ Total number of children on caseload.
- ☐ % of face-to-face time delivered by registered HCPs*.
- ☐ Named staff on each package and dates of training/competency.
- ☐ Unfilled shifts and contingency arrangements, including any subcontracting details.
- ☐ Issues/incidents with narrative on management and mitigations.

Monitoring of provider quality

- ☐ Number of staff per package and % of shifts not covered (excluding hospital admissions/parent-cancelled).
- ☐ Achievement of monthly contacts* and observation-of-practice frequency*.
- ☐ Calls to 24/7 support out of hours*; time to discharge and reasons for delay.

- ☐ National/Network KPIs and locally agreed indicators.
- ☐ Share reports with social care partners for joint packages.

Review and learning.

- ☐ Operate MDT review processes for incidents, near misses, complaints, safeguarding, and Learning from Excellence.
- ☐ Record actions, implement changes, and evidence impact at subsequent reviews.

Key worker core functions

- ☐ Maintain regular contact; provide information, support and advice to family.
- ☐ Liaise with named CCN; keep PCP, Agreement of Care, EHCP, Escalation Plan and risk assessments up to date.
- ☐ Identify responsibilities for equipment and consumables.
- ☐ Inform services/education of changes; initiate MDT planning or discharge planning as required.
- ☐ Initiate/maintain CAF (if applicable); consider and act on safeguarding issues.

Education and training standards

- ☐ Ensure educators are registered professionals with relevant LTV competencies; maintain annual clinical updates and supervision.
- ☐ Deliver three-part training for commissioned adults: general baseline education; patient-specific training from tertiary Centre; shadow shifts (day & night).
- ☐ Document pragmatic plans when hospital attendance for training/shadowing is not feasible; continue ongoing community training post-discharge.
- ☐ If transitioning from nurses to commissioned adults, agree a documented transition plan (e.g., ~6 weeks) and communicate to MDT and family.

** Items marked with an asterisk in the standards apply primarily to Level 2/3 packages.*