

**Protocol for Managing Children with Complex
Health Care Needs in Community Settings**
(including schools, children's centres and other
settings)

DRAFT

Multi Agency Guidance

Working in partnership to improve outcomes for children and families

Managing Children with Health Care Needs in the Community

1. Introduction

- 1.1 This protocol is designed to ensure that children and young people living in Milton Keynes who have complex health needs, which as a consequence require additional support and / or care, are able to access a range of settings within the community. This includes schools, early years settings, and other settings e.g. holiday play schemes and after school clubs.
- 1.2 It provides a framework for a consistent response to the needs of children and young people in a confidential and respectful way to ensure that they have the opportunity to participate in all aspects of community life. This includes children who are dependant on their parents / carers carrying out an invasive clinical procedure which is essential either as part of their routine care or within expected emergency management. For example - children requiring gastrostomy feeds; oxygen therapy or assistance to manage diabetes – see Appendix 1.
- 1.3 The focus of this protocol is to:
 - 1.3.1 Demonstrate a local multi-agency commitment to positively promoting the inclusion of all children with complex health needs and improving efficient multi-agency working in partnership with children and families.
 - 1.3.2 Clarify roles, responsibilities and accountability in enabling children with complex health needs to be fully included in community settings such as schools and a range of childcare settings, for example playgroups and private nurseries.
 - 1.3.3 Clarify for parents/carers and children what can be expected.
 - 1.3.4 Provide a framework within which to manage the risks associated with carrying out clinical procedures that relate to the child, the worker and the organisation.
- 1.4 Children and young people may present with a range of needs, some of which will require clinical interventions. The skills required to meet these needs may:
 - Be routine and easily obtained (Level 1 tasks as described in Appendix 1).
 - Require training from health personnel (Level 2 tasks as described in Appendix 1).
 - Require complex Clinical procedures, which should only be carried out by trained health professionals (level 3 tasks as described in Appendix 1).

This protocol has been developed to address situations where children have additional needs requiring care staff to undertake tasks which require training from health personnel (Level 2 tasks).

2. Background

- 2.1 This protocol is based on information contained within 'Including Me: managing complex health needs in schools and community settings' (2005).
- 2.2 The protocol should be considered along with local and national policies, guidance and initiatives relating to children and young people.
- 2.3 'Including Me' is a practical handbook which provides guidance on managing admissions in a non-discriminatory manner and ensuring that children with complex health needs can

access education and childcare. This protocol should be read alongside 'Including Me' http://www.ncb.org.uk/cdc/resources/including_me.aspx

3. Local Context

- 3.1 This protocol seeks to address challenges identified locally about staff, other than health providers, in settings undertaking clinical tasks to meet the health care needs of children and young people. The protocol aims to assist in clarifying roles and responsibilities to ensure that the health care needs of children who require clinical interventions are safely met.
- 3.2 A more detailed guidance document 'Information and Guidance for Schools, Early Years and other community settings for Children and Young People with medical and physical difficulties' is also available to aid the implementation of this protocol. This guidance document provides information to support settings to meet the needs of children with a range of medical and physical difficulties and includes information on the management and administration of medication. The document can be found at: <http://www.miltonkeynes.gov.uk/inclusion/displayarticle.asp?DocID=35297&ArchiveNumber=>

4. Duties

- 4.1 Most children and young people with complex health needs are likely to meet the definition of a disability in the Equality Act 2010. This gives them protection from discrimination in a whole range of services.
- 4.2 Local authorities, healthcare agencies, schools and early years settings have three key duties:
- To eliminate unlawful discrimination, harassment and victimisation
 - To advance equality of opportunity, including making 'reasonable adjustments' and taking positive action to remove barriers to participation for disabled children
 - To foster good relations between people from different groups.

5. Roles and responsibilities

- 5.1 All settings have a role to play in supporting children's needs however complex. There are many people who, due to their role and proximity to the child with clinical needs, may need to undertake specific tasks. For example, these include individuals in education settings, family homes, play schemes and short break facilities.
- 5.2 Staff working in settings work in partnership with parents and carers who are the legal guardians of their child and have parental responsibility and may where appropriate provide consent to treatment and care on behalf of their child. Parents and carers also have a responsibility to effectively engage with agencies in relation to their child's health care needs.
- 5.3 All agencies should ensure that the child and their parents/main carers are able to fully participate and contribute throughout the process to develop the relevant care plan and are kept informed and updated about their child's health needs.
- 5.4 Accountability for the provision of care rests with individuals within their own organisations. Procedures, policies and professional codes of conduct should include clarity around management supervision, training and review. Each employer (with the exception of local authorities who may self-insure) is required to take out employers' liability insurance to provide cover for staff acting within the scope of their employment.

- 5.5 Individual schools and settings are responsible for ensuring that they employ staff with job descriptions written to cover the tasks required to support this group of children, or have staff who are willing to undertake the tasks on a voluntary basis. This means ensuring they have staff able to undertake the range of Level 1 and 2 tasks outlined in Appendix 1. Head Teachers and Governing Bodies of schools are responsible for their policies and procedures, and for ensuring that these policies comply with current legislation including the Equality Act 2010.
- 5.6 Schools and settings should work in partnership with health professionals to devise care plans and ensure relevant training is provided for staff, so that the needs of individual students can be met.
- 5.7 Schools and settings are responsible for ensuring that staff receive ongoing supervision, a record of training is retained, that they contact health professionals when retraining or updating are due, or if there is a change in the child's condition which requires a review of the care plan.
- 5.8 The Local Authority's Integrated Support and Social Care (ISSC) Division within the Children and Families Service are responsible for funding additional support to schools for children and young people with medical needs and for funding the home tuition service for students with emotional/medical needs. This funding is accessed by application to the SEN and Alternative Education Panels. In pre-school settings, funding for additional support to enable children with medical and physical needs to access education can be applied for through the Inclusion Coordinators based at Galley Hill Education centre.
- 5.9 The Local Authority's Children with Disabilities Team, ISSC, of the Children and Families Service is responsible for funding the social care service provided. The team will ensure that packages of support are commissioned in line with the principles in this protocol.
- 5.10 A range of NHS providers as well as private healthcare providers will have staff with the required skills and competencies to train and supervise staff in other settings to undertake clinical tasks which require training from health personnel (Level 2 tasks described in Appendix 1). The most appropriate provider will depend on the clinical condition and identified funding arrangements.
- 5.11 The healthcare provider will be responsible for the *management* of healthcare staff, *supervision* and *training* of workers undertaking clinical tasks and the *review* of these clinical tasks when it is assessed and agreed that these are to be provided to the child by other agencies.

Management: being accountable for the activity of the health professional who is responsible for the training and support of the worker.

Supervision: the health professional taking responsibility for providing initial supervision for the worker. This includes recording supervision and addressing any issues that arise.

Training: the health professional providing the training should be appropriately qualified and experienced to undertake this role. They should provide a record of the training delivered, and identify when re-training or updating will be required.

Review: any change in the child's medical needs that may impact on the tasks that are being carried out by staff in schools and other settings, should be assessed by the healthcare provider once the change in need is identified to them, and care plans updated accordingly.

6.0 Risk management and assessment

6.1 There is an element of risk involved with many of the tasks carried out to support children with complex health needs. These risks cannot be removed completely, but it is possible to manage them.

For staff, risk management will ensure that:

- Tasks are carried out in the safest way possible
- Any risk to staff is minimised.

For children, risk management will ensure that:

- They are not exposed to unacceptable risks
- They can take part and enjoy all the activities of the school or other setting.

6.2 Risk management processes should be managed in accordance with established procedures in all schools and other settings.

6.3 As part of a risk management process all children with complex needs should have health care plans, specific to their particular needs. The care plan should:

- Clarify for staff, parents/carers and children the level of support a child will receive in any setting
- Identify who is responsible for each task or procedure relating to a particular child
- Identify required training for particular procedures and who will carry out the training.

6.4 It is the responsibility of the school or setting admitting the child to ensure that the plan is developed and put in place, relevant agencies should participate in this multi-agency process.

7.0 Expected outcomes

- Children and young people with complex health needs are fully included in schools, early years and other community settings.
- Parents/carers should feel confident that their child's health care needs will be managed safely.
- Staff in community settings feel confident and fully supported in meeting health care needs of children and young people.
- High quality provision is available in schools, early years and other community settings for those with complex health needs.

8.0 Monitoring and Evaluation

8.1 The management of children with health care needs in community settings will be monitored at a number of levels.

Individual schools and settings should be routinely monitoring to ensure children and young people are not disadvantaged because of their disability or health care needs.

8.2 The Children with Disability Strategy Group will monitor implementation of this protocol.

- 8.3 This protocol should be reviewed bi-annually or earlier if required, by the Children with Disability Strategy Group.

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Appendix 1

Levels of clinical procedures required by children and young people.

Procedures fall broadly into three levels of skill and risk.

Level 1 – Routine and easily acquired skills.

These skills may be already acquired as parents and workers with children. Most children at some time will require tasks carried out at this level. Initial training will be required to reassure staff in carrying out this kind of activity. Ongoing training may be required.

Intimate personal care - assisting with cleaning and changing soiled clothing, changing nappies and sanitary wear in order to keep the child clean and comfortable.

Promoting continence – assisting with toileting regimes, ensuring children have access to appropriate toilets, regular drinks etc.

Assisting a child with eating or drinking – Following a simple plan involving environmental, postural and equipment adaptors to provide independence at meal times.

Dry/wet wrapping for a child with eczema – a prescribed treatment involving dressings for children with severe eczema.

Making up of a routine infant feed – following an instruction as to how much feed and water to mix together.

Moving and handling – assisting a child who may have mobility problems in accordance with local policy.

Undertaking a child's physiotherapy programme – following a simple written programme from Physiotherapy.

Supporting a child's communication programme – following a written programme from a registered Speech & Language Therapist.

Care of a child with epilepsy not requiring emergency medication –this involves measures to ensure the safety of the child during a seizure.

Simple dressings – dressing to skin following a care plan, for example; application of a gauze square with tape including transdermal patches.

Level 2 - Tasks requiring training from health personnel (usually qualified nurses).

These are tasks that need to be carried out regularly, require a small amount of time, privacy, some degree of skill and the use of generic equipment. Specific training will be required in accordance with local guidelines. Some of these tasks could be carried out by the child themselves if of an appropriate age and ability.

The following advisory list of procedures may be safely taught and delegated to non-health qualified staff following a child-specific assessment of clinical risk:

- Administering medicine in accordance with prescribed medicine in pre-measured dose via nasogastric tube, gastrostomy tube, or orally
- Bolus or continuous feeds via a nasogastric tube
- Bolus or continuous feeds using a pump via a gastrostomy tube
- Tracheostomy care including suction using a suction catheter

Emergency change of tracheostomy tube†

Oral suction with a yanker sucker

Injections (intramuscular or subcutaneous). These may be single dose or multiple dose devices which are pre-assembled with pre-determined amounts of medication to be administered as documented in the individual child's care plan (preloaded devices should be marked when to be administered e.g. for diabetes where the dose might be different am or pm. In many circumstances there may be two different pens, one with short-acting insulin to be administered at specified times during the day and another for administration at night with long acting insulin).

Intermittent catheterisation and catheter care

Care of Mitrofanoff

Stoma care including maintenance of patency of a stoma in an emergency situation using for example the tip of a soft foley catheter and replacement of button devices once stoma has been well established for more than 6 months and there have been no problems with the stoma‡.

Inserting suppositories or pessaries with a pre-packaged dose of a prescribed medicine

Rectal medication with a pre-packaged dose i.e. rectal diazepam

Rectal paraldehyde which is not pre-packaged and has to be prepared – permitted on a named child basis as agreed by the child's lead medical practitioner i.e. GP or paediatrician

Manual Evacuation

Administration of buccal or intra-nasal Midazolam and Hypo stat or GlucoGel.

Emergency treatments covered in basic first aid training including airway management

Assistance with inhalers, cartridges and nebulisers

Assistance with prescribed oxygen administration including oxygen saturation monitoring where required

Administration and care of liquid oxygen administration including filling of portable liquid oxygen cylinder from main tank

Blood Glucose monitoring as agreed by the child's lead nursing/medical practitioner i.e. GP, paediatrician or paediatric diabetes nurse specialist

Ventilation care for a child with a predictable medical condition and stable ventilation requirements (both invasive and non-invasive ventilation). NB. Stability of ventilation requirements should be determined by the child's respiratory physician and will include consideration of the predictability of the child's ventilation needs to enable the key tasks to be clearly learnt.

Level 3 - More complex Clinical procedures.

These require more skill and carry a greater degree of risk so can only be carried out by trained health workers.

Assessment of care needs, planning a programme of care or evaluating outcomes of a programme of care

Re-insertion of nasogastric tube

Re-insertion of PEG's or other gastrostomy tubes

Intramuscular and sub-cutaneous injections involving assembling syringe or intravenous, administration

† Routine tracheostomy changes provide an opportunity for a registered practitioner to assess carer competency while also undertaking an assessment of the tracheostomy site

‡ The first time replacement must be undertaken by an appropriately qualified nurse or qualified medical practitioner.

Programming of syringe drivers

Filling of oxygen cylinders (other than liquid oxygen as stated above)

Deep Suctioning (oral suctioning tube beyond back of mouth or tracheal suctioning beyond the end of the trachea tube)

Siting of indwelling catheters

Medicine not prescribed or included in the care plan

Ventilation care for an unstable and unpredictable child

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Appendix 2

Glossary/ Further Jargon Busting

Adrenaline - A hormone that has multiple effects on body systems often used to treat anaphylaxis including increasing the heart rate.

Injection- a method of introducing liquid into the body using a needle and syringe.

Epilepsy - a group of brain disorders characterised by recurrent episodes of seizures, sensory disturbance, abnormal behaviour, loss of consciousness or all of these.

Diazepam - a sedative drug often used to treat prolonged seizures.

Midazolam - a drug often used to treat prolonged seizures or as a short activating sedative for distressing procedures.

Gastrostomy - artificial opening into the stomach through which a patient/ child can be fed or medicated.

Eczema - A group of skin conditions causing hot, itchy and dry skin, when severe the skin can become raw, broken and infected.

Nebuliser - A device used to deliver medicine directly into the lungs by producing a mist that is breathed in.

Catheter - A tubular flexible surgical device used to withdraw or introduce fluids from or into body cavities.

Suppository – Medication in a form that can be introduced into the rectum.

Enema - Introduction of liquid into the bowel through the rectum.

Oxygen – a gas that can be administered via a face mask or nasal prongs.

Suction – The process of removing excess fluids from all areas of the body using a tube attached to a vacuum.

Oral – relating to the mouth.

Nasal – relating to the nose.

Tracheostomy – Surgical opening into the trachea (windpipe).

Stoma – Surgically created opening in an organ.

Mitrofanoff – a surgical opening from the skin to the bladder

Ace Washout – Bowel washout.

Invasive – Involving the insertion of a foreign material into the body.

Non-Invasive – not involving the insertion of foreign material into the body.

Ventilation – The use of a machine to ensure the exchange of O₂ and CO₂ between the lungs and the air.

Diabetes – Disorder of the pancreas which results in altered insulin production which regulates absorption of the amount of sugar in the bloodstream

Dressings – Any material used for covering and protecting a wound or surgically formed opening.

Insulin – Hormone that assists in the regulation of the amount of sugar in the blood. It can be made artificially and used to treat diabetic patients.

Dialysis – A way of removing waste products from the blood and excess fluids from the body when the kidneys have failed.

Nasogastric feeding – Maintaining supplemental nutrition via a thin tube passed down the nose into the stomach.

Controlled Drug – drugs that have been designated as having greater restrictions for prescribing and dispensing by the drug enforcement administration.

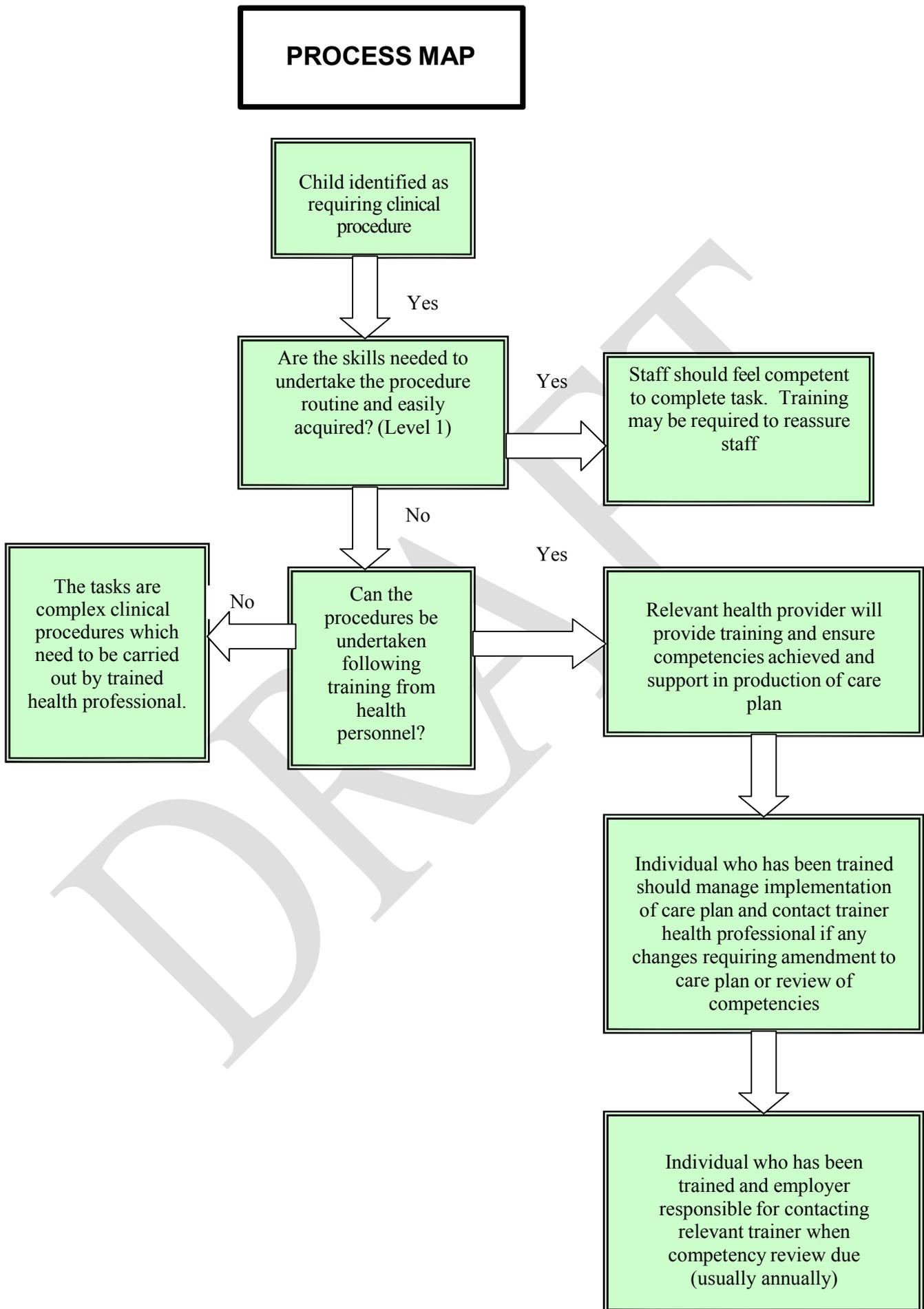
Intravenous – Via a vein.

Cytotoxic – Poisonous to cells.

Venepuncture – Process of obtaining a sample of blood using a syringe and needle, into the vein.

Stridor – noisy breathing

Appendix 3



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