<table>
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<th><strong>Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Complex Feeding) in Community and Education Settings within Leeds</strong></th>
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| **Author** | David Cundall, Community Paediatrician  
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| **Review date** | 3 years from ratification date |
| **Guideline Number** | To be inserted by C-GaP |
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**Appendices**  

- Appendix 1: Equality Impact Assessment (EIA)  
- Appendix 2: Paediatric Speech and Language Therapy Dysphagia Risk Matrix  
- Appendix 3: Examples of and Contact Information for Multi-Agency Staff Groups  
- Appendix 4: Health’s Roles and Responsibilities Summary  
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Abbreviations

EIA: Equality Impact Assessment
MDT: Multidisciplinary Team
NHSLCH: NHS Leeds Community Healthcare
SENCO: Special Education Needs Coordinator
SLT: Speech and Language Therapist

Acknowledgements

This guideline was the result of successful partnership working between health, education, social care, private/voluntary sector colleagues and parents/carers. A special recognition goes out to those individuals who devoted their time and commitment to the development of this essential guideline. This guideline is dedicated to recently retired paediatrician Dr. David Cundall. His passion and enthusiasm for helping disabled children/young people reach their full potential will always be remembered by his patients, their families and his colleagues.
1. Purpose

In Leeds there are approximately 250 children/young people with moderate, major and/or profound dysphagia, 98% of these children/young people are disabled in other ways (NHSLCH, 2008). When swallowing is a problem, the child/young person may not be able to receive adequate nutrition by oral feeding and/or they may be at risk of aspiration (food and/or fluids entering the airways). If aspiration occurs, the child/young person may appear visibly unwell however; this may not be immediately obvious (“silent aspiration”).

Children/young people who have aspirated are often able to clear their own airways by coughing. A small minority of children/young people who have aspirated may develop severe respiratory problems and aspiration can lead to death (Mikita and Callahan, 2010). An increasing number of children/young people with major feeding problems are fed via alternative routes, usually by a gastrostomy tube. The use of tube feeding does not always prevent aspiration as stomach contents can reflux into the oesophagus and airways.

In Leeds most disabled children/young people of school age are educated in “mainstream” settings as part of the Leeds inclusion strategy. Those children/young people who are unable to feed themselves are often fed by teaching assistants employed by the child’s/young person’s school. Teaching assistants work under the supervision of the class teacher with advice from the special education needs coordinator (SENCO), educational psychologist and speech and language therapist.

Social care and the private/voluntary sector my be involved if the child/young person has pre-school education, private school education or short break care.

Following an incident in 2007, NHS Leeds identified dysphagia as a high risk area. The Leeds Disabled Children’s Programme Board has subsequently given its approval to develop an inter-agency guideline. All agencies recognise the importance of a shared approach to ensure best practice which is coordinated, evidence-based and safe.

The purpose of this guideline is to establish a consistent, cohesive approach between health, education, social care and the private/voluntary sector to manage the risks associated with moderate, major and/or profound dysphagia.

All staff employed by NHS Leeds Community Healthcare (NHSLCH), education, social care and the private/voluntary sector must work in concordance with the Leeds Safeguarding Multi-agency Policies and Procedures and local guidelines in relation to any safeguarding concerns they have for children or adults they are in contact with.

2. Scope

This guideline sets out the standards and procedures for any member of staff within NHSLCH, education, social care and the private/voluntary sector, irrespective of age, race, colour, religion, disability, nationality, ethnic origin, gender, sexual orientation or marital status, domestic circumstances, social and employment status, HIV status, gender reassignment, political affiliation or trade union membership.

This guideline is relevant for all professionals within NHSLCH, education, social care and the private/voluntary sector who work with children/young people with moderate, major and/or profound dysphagia. This may include professionals within:
2.1 Health: Speech and language therapists, dieticians, occupational therapists, physiotherapists, paediatricians, health visitors, school nurses, community children’s nurses, clinical psychologists, general practitioners, paediatric surgeons, paediatric radiologists, seating engineers and managers.

2.2 Education: Nursery nurses, teaching assistants, teachers, head teachers, special education needs coordinators (SENCOs), educational psychologists and school governors.

2.3 Social Care: Social work managers and social workers; family placement managers, social workers and carers; residential unit managers and carers and individual support workers and Weekenders commissioned via social care.

2.4 Private/Voluntary Sector: Providers of education, short breaks and/or residential care for children/young people who meet the inclusion criteria and/or organisations which support parents/carers in the care of these children/young people. Examples may include: MENCAP, Weekenders, People in Action, SCOPE, Parent Power, Martin House, short break providers and staff in private nursery/ crèche settings.

3. Equality Impact Assessment (EIA)

3.1 Equality Impact Assessment Summary: The Stage 1 EIA (Appendix 1) highlighted the key equality groups for which this guideline could impact upon: disability, age, race, religious belief and dependants/caring responsibilities. As a result of the EIA upon guideline ratification and subsequent reviews a guideline dissemination process will be implemented. This will include the cascade of information to relevant staff groups and the development and distribution of newsletters/ flyers for parents/carers. The assessment also reiterated the importance of:

- Consulting with the child/young person and parents/carers in the development of the multidisciplinary feeding plan and goal setting.
- Utilisation of an interpreter and translation services for those who have English as a second language.
- Being culturally sensitive when offering advice and scheduling assessments and mealtimes.

3.2 Equality Impact Monitoring: The equality impact of the guideline will be measured every three years in conjunction with the guideline review. Prior to this guideline being developed an audit was conducted against the proposed guideline standards. A re-audit against these standards will be led by health with input from education, social care and the private/voluntary sector. When the guideline is reviewed a current literature search will be conducted, dysphagia specific incidents, complaints and complements (from each agency) reviewed and service user feedback assessed.

4. Mental Capacity Act (Great Britain, Mental Capacity Act 2005)

This Act applies to all persons over the age of 16 who are judged to lack capacity to consent or withhold consent to acts which are considered by health and social care professionals to be in the best interests of their welfare and health.

The Mental Capacity Act 2005 imposes a legal requirement on health and social care professionals to ‘have regard to’ relevant guidance within the Code of Practice when acting or making decisions on behalf of someone who lacks capacity to make the decision for themselves.
Furthermore, they should be able to explain how they had regard to the Code when acting or making decisions.


5. Objectives

1. Outline the roles and responsibilities of health, education, social care and the private/voluntary sector to clarify which staff groups and/or workers are to be involved in the assessment and management of children/young people with moderate, major and/or profound dysphagia (refer to section 8.1 for dysphagia definitions).
2. Develop a process for the development and implementation of multidisciplinary feeding plans to manage the risks and improve outcomes for children/young people with moderate, major and/or profound dysphagia.
3. Implement a multi-agency training programme to promote best practice.

6. Client Group – Inclusion Criteria

6.1 Health
- Children/young people aged 0-18 years (0-19 for those in a SILC setting) with moderate, major and/or profound dysphagia (as per the definitions in section 8.1).
- Children/young people who reside in Leeds and/or have a Leeds GP.
- Children/young people whose health needs are met in a community setting.

6.2 Education
- Children/young people aged 0-19 years with moderate, major and/or profound dysphagia (as per the definitions in section 8.1).
- Children/young people who are educated in Leeds and/or reside in Leeds.

6.3 Social Care
- Children/young people aged 0-18 years with moderate, major and/or profound dysphagia (as per the definitions in section 8.1).
- Children/young people who reside in Leeds.

6.4 Private/Voluntary Sector
- Children/young people aged 0-18 years with moderate, major and/or profound dysphagia (as per the definitions in section 8.1).
- Children/young people who reside in Leeds.

7. Client Group – Exclusion Criteria

7.1 Health
- Children/young people aged 0-18 years with mild dysphagia (as per the definitions in section 8.1).
- Children/young people who are not Leeds residents and do not have a Leeds GP.
- Children/young people whose health needs are met in an acute setting.

7.2 Education
- Children/young people aged 0-19 years with mild dysphagia (as per the definitions in section 8.1).
7.3 Social Care
- Children/young people aged 0-18 years with mild dysphagia (as per the definitions in section 8.1).
- Children/young people who are not Leeds residents.

7.4 Private/Voluntary Sector
- Children/young people aged 0-18 years with mild dysphagia (as per the definitions in section 8.1).
- Children/young people who are not Leeds residents.

8. Multidisciplinary Feeding Plan Implementation

8.1 Dysphagia Definitions: Within this guideline the term dysphagia refers to disorders of the total process of feeding, eating, drinking and/or swallowing. For the purpose of this document the term dysphagia will be subdivided into four descriptor categories: mild, moderate, major and profound. To further assess the risks associated with each descriptor category refer to the Dysphagia Risk Assessment Matrix located in Appendix 2.

8.1.1 Mild Dysphagia:
- Mild delay/occasional sign of dysfunction in oro-motor skills.
- May need texture/utensil/resource modification.
- Takes full balanced diet.
- Good prognosis for oral skills.

8.1.2 Moderate Dysphagia:
- Moderate delay/dysfunction in oro-motor skills.
- Texture/utensil/resource modification necessary.
- Some difficulty maintaining full balanced diet.
- Signs of aspiration on one food type/consistency.

8.1.3 Major Dysphagia:
- Severe oro-motor difficulties/dysfunction.
- Signs of aspiration across more than one food type/consistency.
- Unable to maintain nutrition and/or hydration orally.

8.1.4 Profound Dysphagia:
- Level 4 clinical presentation (i.e. Major) where advice of speech and language therapist (SLT) and multidisciplinary team (MDT) have not been followed.

8.2 Staff Requirements/Training Needs

8.2.1 Level 1: Guideline Dissemination
- **Training Synopsis:** To cascade the information contained in the guideline upon ratification and subsequent reviews.
- **Staffing Groups:** Health, education, social care and private/voluntary sector staff groups whose role may involve working with and/or caring for a child/young person with moderate, major and/or profound dysphagia (Refer to Appendix 3 for multi-agency staff group examples).
- **Training Provider:** Health, education and social care line managers.
- **Training Frequency:** Upon initial release of the guideline and subsequently every 3 years and/or when the guideline is reviewed.
8.2.2 Level 2: Lead Staff Training

**Training Synopsis:** Training outlining the function and purpose of a multidisciplinary team (MDT) feeding plan, identifying which children/young people may benefit from a plan, how plans should be recorded, monitored and reviewed and multi-agency roles and responsibilities.

**Staffing Groups:** Staff responsible for approving and monitoring MDT feeding plans (Refer to Appendix 3 for multi-agency staff group examples).

**Training Provider:** Healthcare professional(s).

**Training Frequency:** For all new starters. Refresher training upon request.

8.2.3 Level 3: Direct Feeding Training

**Training Synopsis:** Knowledge and skills development training to ensure best practice and safety.

**Staffing Groups:** For all staff involved in the direct feeding of and/or oversee the self-feeding of a child/young person with moderate, major and/or profound dysphagia (Refer to Appendix 3 for multi-agency staff group examples).

**Training Provider:** Relevant specialist healthcare professional(s). This is likely to include a speech and language therapist (SLT).

**Training Frequency:** For all new starters and as identified by individual plans and reviews. Refresher training upon request or if a need is identified by any staff/agency.

8.3 Roles and Responsibilities

8.3.1 Overarching Roles and Responsibilities

- It is the responsibility of all staff who are involved in the child’s/young person’s eating and drinking to carry out agreed MDT feeding plan.
- It is the responsibility of all those involved in the child’s/young person’s care to use the appropriate networks and systems to ensure well co-ordinated care and good communication to inform any relevant changes to the child’s/young person’s MDT feeding plan.
- MDT feeding plans are easily accessible for those involved in the feeding of children/young people with moderate, major and/or profound dysphagia.
- MDT feeding plans are agreed and signed off by the child/young person (where applicable), parent/carer and relevant staff members.
- Staff members to seek additional training as required.

8.3.2 Multi-Agency Specific Roles and Responsibilities

- Health’s roles and responsibilities summary located in Appendix 4.
- Education’s roles and responsibilities summary located in Appendix 5.
- Social care’s roles and responsibilities summary located in Appendix 6.

8.4 Multidisciplinary Team (MDT) Feeding Plan Implementation

8.4.1 Implementation Prior to the Child's/Young Person’s Arrival at the Setting

<table>
<thead>
<tr>
<th>Action</th>
<th>Rationale</th>
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| Multi-agency meeting (in consultation with parent/carer and/or child/young person) involving relevant professionals | ▪ To engage relevant parties.  
▪ To minimise risk and promote the safe feeding of the child/young person. |
and setting management. ▪ Best practice.

Individual MDT feeding plan with timescales developed and agreed. ▪ To minimise risk and promote the safe feeding of the child/young person. ▪ Best practice.

Copies of the MDT feeding plan sent to the family, relevant professionals and setting management. ▪ To inform all relevant parties of the agreed plan. ▪ Promote multi-agency working.

Staff to jointly ensure appropriate equipment/utensils are in place upon arrival. ▪ Enable the child/young person to receive optimum feeding upon arrival. ▪ Promote multi-agency working.

Setting staff to determine an easily accessible location for the MDT feeding plan to be kept. ▪ To minimise risk and promote the safe feeding of the child/young person. ▪ Best practice.

Staff responsible for feeding/supporting the child/young person are in place. ▪ Enable the child/young person to receive optimum feeding upon arrival. ▪ To promote safe feeding upon arrival.

Staff responsible for feeding/supporting to receive the appropriate level of training - initiated by the setting manager and/or individual. ▪ To minimise risk and promote the safe feeding of the child/young person upon arrival. ▪ Enable the child/young person to receive optimum feeding upon arrival.

Staff responsible for feeding/supporting to receive copy of the MDT feeding plan from the setting manager. ▪ To inform all relevant parties of the agreed plan. ▪ Assure appropriate action is taken.

- Corresponding flowchart for the implementation process prior to the child's/young person’s arrival at the setting is located in Appendix 7.
- MDT feeding plan example located in Appendix 8.
- MDT Feeding Plan Table Mat example located in Appendix 9.

8.4.2 Implementation & Monitoring While the Child/Young Person is in the Setting

<table>
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<th>Action</th>
<th>Rationale</th>
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<tr>
<td>MDT feeding plan implemented and easily accessible for staff responsible for feeding/supporting the child/young person.</td>
<td>▪ To minimise risk and promote the safe feeding of the child/young person. ▪ Enable the child/young person to receive optimum feeding. ▪ Best practice.</td>
</tr>
<tr>
<td>MDT feeding plan being followed by the staff feeding/supporting the child/young person.</td>
<td>▪ To minimise risk and promote the safe feeding of the child/young person. ▪ Enable the child/young person to receive optimum feeding. ▪ Best practice.</td>
</tr>
<tr>
<td>MDT review of the child's/young person’s feeding plan, needs and skills to be reviewed within the agreed timescales (This maybe in conjunction with existing reviews).</td>
<td>▪ To minimise risk and promote the safe feeding of the child/young person. ▪ Enable the child/young person to receive optimum feeding. ▪ Promote multi-agency working. ▪ Best practice.</td>
</tr>
</tbody>
</table>
| MDT feeding plan revised as necessary. Copies of the revised MDT feeding plan sent to the family, relevant professionals and setting management. | ▪ To minimise risk and promote the safe feeding of the child/young person.  
▪ Enable the child/young person to receive optimum feeding.  
▪ Promote multi-agency working.  
▪ Best practice. |
| --- | --- |
| If the MDT feeding plan has not been successfully implemented the setting management is to provide a copy of the MDT feeding plan to the feeding/supporting staff and to monitor if the plan is understood and implemented. | ▪ To minimise risk and promote the safe feeding of the child/young person.  
▪ Enable the child/young person to receive optimum feeding.  
▪ Assure appropriate action is taken. |
| If the MDT feeding plan is not being followed by the staff feeding/supporting the child/young person in the setting, management is to provide a copy of the MDT feeding plan to the feeding/supporting staff and to monitor if the plan is understood and implemented. If the plan is still not implemented the member of staff is to be appropriately managed through agency specific procedures. | ▪ To minimise risk and promote the safe feeding of the child/young person.  
▪ Enable the child/young person to receive optimum feeding.  
▪ Assure appropriate action is taken. |
| ONLY appropriately trained staff can conduct the feeding. | ▪ To minimise risk and promote the safe feeding of the child/young person. |
| If further training is required the setting manager and/or individual is to initiate training via the relevant health professional(s). | ▪ To minimise risk and promote the safe feeding of the child/young person. |

- Corresponding flowchart for the implementation and monitoring process while the child/young person is in the setting is located in Appendix 10.
- MDT feeding plan example located in Appendix 8.
- MDT Feeding Plan Table Mat example located in Appendix 9.

9. Equipment

9.1 Specialist Equipment: Specialist equipment may be required for child/young person. Inexpensive items maybe purchased through any of the agencies’ non-pay budgets. More expensive equipment is purchased through the multi-agency equipment group. Examples of specialist equipment may include:

▪ Seating equipment  
▪ Medical equipment  
▪ Specialist utensils  
▪ Use of thickeners for texture modification (As prescribed by the medical practitioner)

Training specific to specialist equipment to be provided by the equipment supplier.

10. Risk Assessments

10.1 Assessing Dysphagia Risks: Risk assessments should be child/young person specific and take into consideration environmental, clinical and intervention risks. Children/young people and their parents/carers must be informed of any risks as appropriate. The Paediatric
Speech and Language Therapy Dysphagia Risk Matrix (Appendix 2) is a speech and language therapy specific tool derived from the Leeds PCT Risk Matrix which is commonly utilised when assessing children/young people with dysphagia.

11. Audit and Monitoring

11.1 Process: The audit and monitoring process will be led by health (initiated by the Children’s Therapy Head of Service or equivalent) with input from education, social care and the private/voluntary sector. The guideline will be reviewed every three years. When the guideline is reviewed a current literature search will be conducted, dysphagia specific incidents, complaints and complements (from each agency) reviewed and service user feedback assessed.

11.2 Audit Proposal (Located in Appendix 11): To assess the implementation of MDT feedings plans to ensure that children/young people with moderate, major and/or profound dysphagia receive:
- A MDT assessment when their feeding difficulty is recognised and/or alters.
- A timely, MDT review of their growth and feeding routine.
- An agreed MDT feeding plan for which there is multi-agency implementation and responsibility.
12. References


## Appendix 1: Equality Impact Assessment

### PRO-FORMA FOR THE INITIAL EQUALITY IMPACT ASSESSMENT

<table>
<thead>
<tr>
<th>1. Department</th>
<th>NHS Leeds Community Healthcare, social care, education and the private/voluntary sector</th>
<th>2. Section</th>
<th>NHS Leeds Community Healthcare: Children’s Therapy</th>
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<tbody>
<tr>
<td>3. Who is responsible for the Assessment?</td>
<td></td>
<td>4. Lead Officer</td>
<td>Liz Franklin</td>
</tr>
<tr>
<td>Katherine Slagle</td>
<td></td>
<td></td>
<td>David Cundall, Barbara Shaw, John Chadwick, Jill Crampton, Verena Beard, Jen McAnuff and Helen Edmunds</td>
</tr>
<tr>
<td>6. Name of the policy/strategy/project or service to be assessed</td>
<td>Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Swallowing Difficulties) in Community and Education Settings within Leeds</td>
<td>7. Is this a new or existing policy/strategy/project or service</td>
<td>New</td>
</tr>
<tr>
<td>8. Date of Assessment</td>
<td>2.7.2010</td>
<td></td>
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<tr>
<td>9. Describe the aims, objectives and purpose of the policy/strategy/project or service</td>
<td>1. Outline the roles and responsibilities of health, education, social care and the private/voluntary sector to clarify which staff groups are to be involved in the assessment and management of children/young people with moderate, major and/or profound dysphagia. 2. Develop a process for the development and implementation of multidisciplinary feeding plans to manage the risks and improve the outcome for children/young people with moderate, major and/or profound dysphagia. 3. Implement a multi-agency training programme to promote best practice.</td>
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<tr>
<td>10.a What data do you have that you can draw upon to support this assessment?</td>
<td>1. One to One Patient/Carer Consultations 2. NHSLCH speech and language therapy patient database 3. Academic Journals 4. Royal College of Speech and Language Therapists 5. NPSA Guidelines for Adults 6. Office for National Statistics</td>
<td></td>
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<tr>
<td>10.b What does this data say?</td>
<td>1. <strong>One to One Patient/Carer Consultations</strong>: Parents/carers are relatively happy with the care their children/young people are receiving however, this guideline could have a positive impact for those children/young people attempting to access short breaks and this guideline could help increase provision. In general parents/carers are supportive of the rationale behind the</td>
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2. NHSLCH Speech and Language Therapy patient database: In Leeds there are approximately 250 children/young people with moderate, major and/or profound dysphagia, 98% of these children/young people are disabled in other ways.

3. Academic Journals
   - Diagnosis and Treatment of Feeding Disorders in Children with Developmental Disabilities (Pediatrics, Volume 108 No.3, September 2001, Pages 671-676): In children with developmental disabilities, diagnosis-specific treatment of feeding disorders results in significantly improved energy consumption and nutritional status. These data also indicate that decreased morbidity (reflected by a lower acute care hospitalization rate) may be related, at least in part, to successful management of feeding problems. Children with developmental disabilities are at increased risk for developing feeding-related difficulties, including gastroesophageal reflux (GER), oral motor dysfunction, pharyngoesophageal dyskinesia, and aversive feeding behaviour. Protein energy intake and nutritional status often are compromised as a consequence of feeding impairment, particularly among the most severely disabled patients.

   - Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study (Developmental Medicine & Child Neurology, Volume 42 Issue 10, Pages 674 – 680): The results highlight that feeding problems in children with neurological impairment are common and severe, causing parental concern. Many of these children would benefit from nutritional assessment and management as part of their overall care.

   - Feeding Disorders in Children With Developmental Disabilities (Infants & Young Children: (October/November/December 2003 - Volume 16 - Issue 4 - p 317-330): Feeding disorders represent major clinical problems that complicate the management of infants and children with neurodevelopmental disabilities. If left untreated, oral-motor, swallowing and gastroesophageal function abnormalities lead to cachexia and poor growth, hinder developmental performance and increase medical and behavioral morbidity. 30% to 90% of individuals with major motor and/or cognitive disabilities exhibit feeding difficulties, and evidence of malnutrition has been reported in up to 90% of nonambulatory children with cerebral palsy.

   - Management of pediatric dysphagia (Otolaryngologic Clinics of North America, Volume 31, Issue 3, Pages 453-476): Optimal management strategies are critical for infants and children with feeding and swallowing problems. Management decisions are made best through a team approach in which caregivers participate with medical and educational professionals to work toward maximizing each child's nutritional status in the context of safe and efficient feeding. These management decisions are typically made on the basis of clinic feeding observations and assessments.
4. Royal College of Speech and Language Therapists:
   - Dysphagia Risk Assessment (2007): This document provides a guide to levels of risk of negative health consequences from dysphagia and identifies the factors that increase the risk of negative health consequences arising from a person’s dysphagia. The negative health consequences are asphyxiatiion and/or choking episode, aspiration incidents, dehydration and poor nutritional status. These factors are not related to the severity of the dysphagia itself but to other intrinsic and extrinsic factors which may exacerbate dysphagia risks. These factors affect the predictability of the person’s presentation and interact with the dysphagia. High risk and low risk are easier to manage than fluctuating risk i.e. the person’s risk varies for any intrinsic or extrinsic factor from meal to meal or day to day.
   - RCSLT Resource Manual for Commissioning and Planning Services for SLCN: Dysphagia. Although this manual is predominantly aimed at adults it provides an well rounded overview of dysphagia i.e. incidence, implications, interventions, etc.

5. National Patient Safety Agency (NPSA) Guidelines for Adults: Feeding, swallowing and nutritional problems have a high prevalence among people with learning disabilities. They can have serious repercussions including poor nutritional status, dehydration, aspiration and asphyxiatiion. They can be life threatening or lead to life threatening problems. Adults with cerebral palsy and those with severe intellectual and physical disabilities have a high incidence of dysphagia and patients with spastic quadriparesis are at particular risk of aspiration. Although there is limited research into people with learning disabilities who have dysphagia, there is evidence that successful management decreases risk.

6. NHS Evidence: Dysphagia in children with severe generalized cerebral palsy and intellectual disability. 166 children (85 males, 81 females) with Gross Motor Function Classification System Level IV or V and IQ<55, mean age 9 years 4 months (range 2y 1mo–19y 1mo):
   - 1% no dysphagia,
   - 8% mild dysphagia,
   - 76% moderate to severe dysphagia,
   - 15% profound dysphagia (receiving nil by mouth),
   - Prevalence of dysphagia 99%. Dysphagia positively related to severity of motor impairment, and to higher weight for height.

6. Office for National Statistics
   http://neighbourhood.statistics.gov.uk/dissemination/LeadTableView.do?a=3&b=276810&c=Leeds&d=13&r=1&e=13&f=25403&o=280&g=382985&i=1001x1003x1004x1005&m=1809&s=128506537338&enc=1&adminCondld=25403&printTable=Print+this+table

   Disability and Ethnicity Data for Children in Leeds:
   Office for National Statistics:
   - Disability Allowance (August 2009 Data): In Leeds there are 3,129 children under 16 claiming Disability Living Allowances. This is 8.54% of the over all 36,640 people in
Leeds claiming Disability Living Allowances.

- Ethnicity (June 2007 Data): 15.31% of people 0-15 years of age consider themselves to be “Non-White”.
- Gender (June 2009 Data): 49% of the female population of Leeds is 0-19 years of age. 51% of the male population of Leeds is 0-19 years of age.
- Children with Dysphagia (NHSLCH SLT Data): In Leeds there are approximately 250 children/young people with moderate, major and/or profound dysphagia, 98% of these children/young people are disabled in other ways.

Therefore for Children in Leeds with Dysphagia it is Assumed:

- Disability Allowance: Approximately, 8% of children with dysphagia in Leeds claim disability allowance.
- Ethnicity: Approximately, 38 children with dysphagia in Leeds are from a minority ethnic group.
- Gender: Approximately, 122 children are female and 128 are male.

11.a What recent consultation/involvement has been undertaken that you could draw upon to support this assessment and who was it with?

| 1. Disabled Children's Programme Board |
| 2. One to One Consultations have been conducted with parents/carers under the care of the following NHSLCH teams: speech and language, occupational therapy dietetics and nursing. |
| 3. NHSLCH teams (speech and language, occupational therapy dietetics, nursing and medics) have discussed the relevance of the guideline at meetings. |
| 4. Barbara Shaw: Interim Head of Disability Services (Social Care) |
| 5. The Assessment and Management of Disabled Children with Feeding Audit conducted by Dr. Griffin (NHSLCH). |

11.b What did they say?

| 1. Disabled Children's Programme Board: Following an incident in 2007, NHS Leeds has identified dysphagia as a high risk area. The programme board has given its approval to develop an inter-agency/multi-agency guideline. |
| 2. One to One Patient/Carer Consultations: Parents/carers are relatively happy with the care their children/young people are receiving however, this guideline could have a positive impact for those children/young people attempting to access short breaks and this guideline could help increase provision. In general parents/carers are supportive of the rationale behind the document. |
| 3. NHSLCH team meetings: The context of the guideline has been discussed at various team meetings. Comments from the Medics meeting on 19.7.2010 include: How often do we monitor growth (this is case-dependent) and how do we monitor growth (literature suggests that some conventional measures are less appropriate for this population). |
| 4. Barbara Shaw Interim Head of Disability Services (Social Care): Barbara felt that this guideline would be critical for those children/young people attempting to access short breaks as this is a liability at the moment. This guideline would be beneficial as it would outline training |
functions, roles and responsibilities which could potentially increase short break provision.

5. **Audit:** Children/young people seen within Broomfield’s feeding clinic received limited MDT input at diagnosis and then at approximately 18 monthly intervals. There is little evidence of multi-agency working/feeding plans.

### 12.a Are there any experts/relevant groups who you can approach to explore their views?

<table>
<thead>
<tr>
<th>Expert/Group</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>David Cundall, Community Paediatrician</td>
<td>NHSLCH: Fully supports and is involved in the development of this guideline.</td>
</tr>
<tr>
<td>Liz Franklin, Speech and Language Therapist</td>
<td>NHSLCH: Fully supports and is involved in the development of this guideline.</td>
</tr>
<tr>
<td>NHSLCH Occupational therapy, dietetics, nursing, speech and language, psychology and paediatric teams.</td>
<td>NHSLCH Multi-Professional Teams (as above 12a): Fully support and are involved in the development of this guideline. They have developed roles and responsibilities for each discipline.</td>
</tr>
<tr>
<td>Barbara Shaw, Interim Head of Disability Services (Social Care)</td>
<td>NHSLCH Medics: Have been consulted in the development of this guideline, feedback as per 11b.</td>
</tr>
<tr>
<td>NHSLCH Medics</td>
<td>Val Hewison, Carers Leeds: Will be providing feedback via email and will attend future meetings.</td>
</tr>
<tr>
<td>Parents/carers of children/young people with dysphagia</td>
<td>Parent/carers: Have been consulted with in the development of this guideline and have been asked questions regarding the guideline proposal, how it can benefit their children/young people and other information/feedback to supplement the guideline.</td>
</tr>
</tbody>
</table>

### 12.b Please give details of who you have approached and what they said:

<table>
<thead>
<tr>
<th>Expert/Group</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>David Cundall, Community Paediatrician NHSLCH</td>
<td>NHSLCH: Fully supports and is involved in the development of this guideline.</td>
</tr>
<tr>
<td>Liz Franklin, Speech and Language Therapist NHSLCH</td>
<td>NHSLCH: Fully supports and is involved in the development of this guideline.</td>
</tr>
<tr>
<td>NHSLCH Multi-Professional Teams (as above 12a)</td>
<td>NHSLCH Medics: Have been consulted in the development of this guideline, feedback as per 11b.</td>
</tr>
<tr>
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<td>Parents/carers</td>
<td>Parents/carers: Have been consulted with in the development of this guideline and have been asked questions regarding the guideline proposal, how it can benefit their children/young people and other information/feedback to supplement the guideline.</td>
</tr>
</tbody>
</table>

### 13.a Taking into account the information gathered:

**Could** this policy/strategy/project or service impact on any of the following groups differently?

- Yes this guideline could potentially impact upon the following equality groups: disability, age, race, religious belief and dependants/caring responsibilities.

**Could** any of the following groups experience of this policy/strategy/project or service be different?

- Individuals who have English as a second language, or are from a culture which have particular beliefs and customs associated with eating may have more difficulty in

### 13.b Where Negative impact has been identified please explain below what action you will take to mitigate this.

- Launch events will be organised within the respective agencies making use of existing multi-agency meetings to promote the guideline and importance of the training.
- Parents/carers have been involved in
accessing services and co-operating fully in detailing their symptoms and participating in an assessment.
- Each child/young person would receive their own personalised feeding plan specific to their health needs.
- The purpose of this guideline is to have agreed, MDT feeding plans to standardise care to create a safe feeding environment for the children/young people of Leeds with moderate, major and/or profound dysphagia.
- One of the objectives of this guideline is to have the relevant staff in each of the agencies trained and implementing MDT feeding plans.

Could this different impact be negative?
- Implementation of this new guideline will require additional training for identified staff groups. This additional training requirement could be seen as an inconvenience for some staff.
- Parents/carers could disagree with the MDT feeding plans.
- Teams must take into consideration cultural requirements and religious beliefs of all patients.
- There is a time and cost implication when working with interpreters/co-workers, for example, in taking a case history, completing a full assessment in all languages spoken by the individual (if appropriate) and their family.

Please explain for the groups below, drawing on evidence that supports your view:

<table>
<thead>
<tr>
<th>1. Age</th>
<th>This guideline is specific to children/young people aged 0-18 (health &amp; social care) or 0-19 (education) with moderate, major and/or profound dysphagia. Children/young people with developmental disabilities are at increased risk for developing feeding-related difficulties. Optimal management strategies are critical for children with feeding and swallowing problems.</th>
</tr>
</thead>
</table>
| 2. Dependants/caring responsibilities | Social care staff i.e. childminders, foster carers, residential home staff and play scheme staff could potentially have caring responsibilities for the development of the proposed guideline. Upon completion of the guideline a patient newsletter will be developed and distributed to: Display how the parents/carers ideas shaped the guideline and to inform parents/carers who weren’t involved in the initial consultation.
- Parents/carers will be consulted with regards to their child’s/young person’s feeding plan and goal setting. The feeding plan will be signed off by the parent/carer.
- If the parents/carers disagree with the MDT feeding plan they will be given the opportunity to seek a second opinion.
- An interpreter and translation services may be utilised to assist in the assessment and translation of the feeding plan.
- Advice, timings of assessments and mealtimes need to be culturally sensitive.
- Staff awareness regarding ethnicity/religious beliefs to be raised during training sessions. |
### 3. Disability

In Leeds there are approximately 250 children/young people with moderate, major and/or profound dysphagia, 98% of these children/young people are disabled in other ways. 30% to 90% of individuals with major motor and/or cognitive disabilities exhibit feeding difficulties, and evidence of malnutrition has been reported in up to 90% of nonambulatory children/young people with cerebral palsy. One study found that 99% of children with severe generalized cerebral palsy and intellectual disability had dysphagia.

### 4. Gender

Approximately, 122 children are female and 128 are male. This is relatively a 50/50 split.

### 5. Race

Approximately, 38 children (15.31%) with dysphagia in Leeds are from a minority ethnic group (it is assumed the parents/carers would have a similar race and/or religious belief). Many individuals who have English as a second language, or are from a culture which have particular beliefs and customs associated with eating, will require specialist and sensitive consideration.

### 6. Religious Belief

### 7. Transgender or Transsexual

### 8. Sexual Orientation

<table>
<thead>
<tr>
<th>14.a How could this policy/strategy/project or service impact on relationships and attitudes between different groups of people? Could this impact be negative?</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please explain: Implementation of this new guideline will require additional training for identified staff groups. This additional training requirement could be seen as an inconvenience for some staff. Parents/carers could disagree with the MDT feeding plans. Individuals who have English as a second language, or are from a culture which have particular beliefs and customs associated with eating may have more difficulty in accessing services and cooperating fully in detailing their symptoms and participating in an assessment.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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| 14.b What action will you take to mitigate any negative impact or to promote equality and good relations? | • Upon guideline ratification and subsequent reviews a guideline dissemination process will be implemented. This will include the cascade of information to relevant staff groups.  
• Parents/carers have been involved in the development of the proposed guideline. Upon completion of the guideline a patient newsletter will be developed and distributed (action plan) to display how the parents/carers ideas shaped the guideline and to inform parents/carers who weren’t involved in the initial consultation.  
• Parents/carers will be consulted with regards to their child’s/young person’s feeding plan and goal setting. The feeding plan will be signed off by the parent/carer.  
• Appropriate interpreter/translation services will be utilised (if appropriate) to assist in the assessment and translation of the feeding plan.  
• Advice, timings of assessments and mealtimes need to be culturally sensitive.  
• Staff awareness regarding ethnicity/religious beliefs to be raised during training sessions.  
• Capture and monitor ethnicity data for dysphagia patients.  
• Staff to be informed/reminded how to access interpreter/translation services. |

| 15.a In relation to each of the groups, are there any areas where you are unsure about the impact and more information is needed? | NO |
| 15.b. How are you going to gather this information? | N/A |

| 16.a As a result of this assessment is a stage 2 assessment necessary | YES | NO |
| Please explain your answer: This guideline is for a small cohort of patients in Leeds. The processes outlined in the guideline have been taking place informally and the purpose of the guideline is to formalise the process between health, education and social care. The clinicians and teams involved in the development of the guideline are experts in their respective fields and understand the needs and health risks associated with this group of children/young people. |

| 16.b Date on which the stage two assessment to be started | N/A |
| 17 Has the monitoring pro forma at appendix one of this toolkit been completed (please submit with this assessment) | Yes | No |
### Pro-forma for identifying monitoring requirement of a policy/strategy/project or service

<table>
<thead>
<tr>
<th>Directorate</th>
<th>NHSLCH, social care, education and the private/voluntary sector</th>
<th>Section</th>
<th>NHS Leeds Community Healthcare: Children’s Therapy</th>
<th>Person responsible for the assessment</th>
<th>Katherine Slagle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of the policy/strategy/project or service to be assessed</td>
<td>Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Swallowing Difficulties) in Community and Education Settings within Leeds</td>
<td>Date of assessment</td>
<td>2.7.2010</td>
<td>Is this a new or existing policy/strategy/project or service</td>
<td>New</td>
</tr>
<tr>
<td><strong>New guideline</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Please state clearly what monitoring arrangements have been established to monitor the impact of the policy/strategy/project or service (continue on a separate sheet if needed)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior to this guideline being developed an audit was conducted against the proposed guideline standards. A re-audit against these standards will be conducted by health (joint responsibility of the senior Speech and Language Therapist with responsibility for dysphagia and the paediatrician who leads on disability) with input from education, social care and ideally the private/voluntary sector. The guideline will be reviewed every three years. Each time the guideline is reviewed a current literature search will be conducted, dysphagia specific incidents and complaints (from each agency) will be reviewed and service user feedback will be assessed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Do you consider these arrangements to be adequate?</strong></td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **Who will be responsible for the monitoring of the policy/strategy/project or service?** |
| Health (as per above) with input from education, social care and the private/voluntary sector as this is a multi-agency guideline. |

| **If no monitoring arrangements have been made please state clearly what will be established to monitor the policy/strategy/project or service** |
| N/A |

| **Please state the date on which the monitoring will be established** |
| Monitoring will be established the date the guideline is ratified by C-GaP. |

| **Existing policy/strategy/project or service** |
| |

<p>| <strong>Please state clearly what monitoring arrangements were in place to monitor the impact of the policy/strategy/project or service? (continue on a separate sheet if necessary)</strong> |
| N/A |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>As a result of undertaking the EIA, please state clearly what additional monitoring systems will be established</td>
<td>N/A</td>
</tr>
<tr>
<td>Please state the date on which the monitoring will be established</td>
<td>N/A</td>
</tr>
<tr>
<td>In both cases</td>
<td></td>
</tr>
<tr>
<td>Please state clearly how you will publish the results of the monitoring with regard to this policy/strategy/project or service</td>
<td>The results will be summarised and added as appendices to the guideline.</td>
</tr>
</tbody>
</table>

Signed (Completing Officer): Katherine Slagle

Signed (Lead Officer): Liz Franklin
Appendix 2: Paediatric Speech and Language Therapy Dysphagia Risk Matrix

1. Introduction
This Risk Matrix is adapted from the Leeds PCT Risk Matrix from February 2008, to apply specifically to SLTs who work with children/young people with dysphagia. There exist various types of risks, such as environmental (to do with the physical environment), clinical (to do with the particular condition of the patient), and intervention (to do with the risks of what we do). The risks for the child/young person are mainly to do with the difficulties inherent in the condition, and as such are not clinical risks run by the PCT. Our intervention is not likely to be high in risk, and should in fact reduce the clinical risk to the child/young person. The risk taken when parents/carers do not follow our advice is a separate issue, as they are neither risks inherent in the condition, nor risks of our intervention. This should be reflected in the Matrix.

Complete a risk matrix for every child/young person seen. If after our advice the child/young person is still in the red area, inform your line manager and complete a PCT Risk Assessment Form (attached and on intranet)

2. Risk Score (Likelihood x Consequence = Risk Score)
A risk scoring system is a simple form of quantified risk assessment, the higher the score the greater the risk. The following tables provide guidance on the suggested response for various bands of risk.

<table>
<thead>
<tr>
<th>Likelihood Table</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assessment/Consequence Table</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PCT Stated Action</th>
<th>SLT action, post advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>RED 25</td>
<td>PROHIBITED; STOP ACTIVITY AND CONTACT EXECUTIVE DIRECTOR.</td>
</tr>
<tr>
<td>RED 16-20</td>
<td>Very High Priority; reduce urgently involving Senior Management.</td>
</tr>
<tr>
<td>RED 15</td>
<td>High Priority; reduce promptly involving Line Management.</td>
</tr>
<tr>
<td>AMBER</td>
<td>Medium priority; reduce through simple, low-cost options.</td>
</tr>
<tr>
<td>GREEN</td>
<td>Low priority; accept unless easily improved.</td>
</tr>
</tbody>
</table>
LEEDS PCT SPEECH AND LANGUAGE THERAPY PAEDIATRIC DYSPHAGIA SERVICE

**RISK ASSESSMENT MATRIX**

<table>
<thead>
<tr>
<th>Likelihood ▼</th>
<th>Matrix</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Almost Certain</td>
<td>[5,10,15,20,25]</td>
</tr>
<tr>
<td>4. Likely</td>
<td>[4,8,12,16,20]</td>
</tr>
<tr>
<td>3. Possible</td>
<td>[3,6,9,12,15]</td>
</tr>
<tr>
<td>2. Unlikely</td>
<td>[2,4,6,8,10]</td>
</tr>
<tr>
<td>1. Rare</td>
<td>[1,2,3,4,5]</td>
</tr>
</tbody>
</table>

**Assessment shows/Consequence**

1. **Negligible**
   - Takes full balanced diet.
   - Feeding skills within normal limits.

2. **Minor**
   - Mild delay/occasional sign of dysfunction in oro-motor skills.
   - May need texture/utensil/resource modification.
   - Takes full balanced diet.
   - Good prognosis for oral skills.

3. **Moderate**
   - Moderate delay/dysfunction in oro-motor skills.
   - Texture/utensil/resource modification necessary.
   - Some difficulty maintaining full balanced diet.
   - Signs of aspiration on one food type/consistency.

4. **Major**
   - Severe oro-motor difficulties/dysfunction.
   - Signs of aspiration across more than one food type/consistency.
   - Unable to maintain nutrition/Hydration.

5. **Profound**
   - Level 4 clinical presentation (ie Major) where advice of SLT/Team has not been/will not be followed.

---

Risk Rating pre-advice: …………………… Risk rating post -advice: ……………………

Has advice been followed? YES / NO (NB: Failure to follow advice may result in no change in risk rating)
Appendix 3: Examples of and Contact Information for Multi-Agency Staff Groups Involved in Guideline Dissemination and Training

**Examples:** This is not a definitive list but should provide assistance in identifying staff specific requirements and training.

**Level 1 Guideline Dissemination:** Health, education, social care and private/voluntary sector staff groups whose role may involve working with and/or caring for a child/young person with moderate, major and/or profound dysphagia. Guideline dissemination maybe applicable for those multi-agency staff groups listed in Section 2 (Guideline Scope).

**Level 2 Lead Staff Training:** Head teachers/school management teams, SENCOs, children centre managers, residential unit managers, family placement managers and social work managers.

**Level 3 Direct Feeding Training:** Health care support workers, non-teaching assistants, lunchtime staff/supervisors, playscheme workers, teachers, residential workers, family placement carers, individual support workers, weekenders, child minders and nursery nurses.

**Contact Information:**

**Health:** NHS Leeds Community Healthcare Speech and Language Therapy Team
  - Telephone: 0113 305 5101
  - Hours of Operation: Monday – Friday, 8.30am – 5.30pm

**Education:**
  - Telephone: 0113 395 1103
  - Hours of Operation: Monday – Friday, 9.00am – 5.00pm

**Social Care:**
  - Telephone: 0113 22 43365
  - Hours of Operation: Monday – Friday, 9.00am – 5.00pm
Appendix 4: Health’s Roles and Responsibilities Summary

**Clinical Psychologists:**
- Recognise the anxiety that having a child/young person with feeding difficulties can cause parents/carers.
- Assist families in understanding the pressure this anxiety can cause and the impact of this on the child’s/young person’s eating behaviours.
- Help families identify the root of this anxiety, and understand its beginnings and the role it has in the child's/young person’s current feeding difficulties.
- Signpost parents/carers to support services as appropriate.
- Assist in reducing any anxieties exhibited by the child/young person.
- Advise jointly with other professionals on any level of developmental delay the child/young person may show, and the impact of these on feeding development.
- Help families understand sensory developmental processes, jointly with other professionals, and the impact of disruption to these on feeding development where necessary.
- Help families recognise any difficulties or concerns with eating they may have themselves and how these may impact on the child/young person.
- Assist in enabling families to develop healthier feeding routines and more relaxed, enjoyable mealtimes.

**Dieticians:**
- Identify children/young people at risk of dysphagia and refer them to the appropriate services.
- Assess children/young people and advise on suitable diet, in conjunction with SLT colleagues, to maximise safety and ensure eating and drinking remains an enjoyable and social experience.
- Advise on texture modification, jointly with SLTs.
- Ensure that an adequate diet is taken to support appropriate growth and to provide essential nutrients and to advise on suitable fortification and supplementation of diet where necessary.
- Advise on fluid intake and support the provision of thickened fluids where necessary.
- Monitor and review both orally and enterally fed children using a variety of tools (including anthropometry, biochemistry and multidisciplinary assessment).
- Advise, initiate and support joint decision making regarding enteral feeding.
- Assess requirements and prescribe enteral feeding regimens for children/young people where necessary.
- Act as key link with the home enteral feeding service provider and direct this provision.
- Support multi-agency and multidisciplinary training regarding all aspects of dysphagia and enteral feeding.

**Occupational Therapists:**
- Be aware when a child/young person receiving occupational therapy has/is suspected of having dysphagia and communicate with the MDT as appropriate.
- Assess the child’s/young person’s self-feeding and mealtime participation in the home and education environment.
- Identify factors pertaining to the child’s/young person’s social, cultural and physical environments and their mealtime activities that may be impacting on their self-feeding and mealtime participation.
- Provide general advice to families on developing self-feeding skills and participating at mealtimes.
- Engage families and the child/young person where possible in goal-setting for self-feeding and mealtime participation in collaboration with the MDT (being aware of safety priorities).
- Provide specific advice on established goals in collaboration with the MDT including positioning, sensory tolerance and processing, motor skills, visual support, routines, environmental distractions, time available, expectations and grading and opportunities for self-feeding.
- Assess for assistive technology to support safety, self-feeding and joining in at mealtimes e.g. seating and tables, adapted utensils and/or powered devices.
- Contribute to established eating and drinking guidelines as appropriate.
- Contribute to multidisciplinary feeding training as appropriate.

**Paediatricians:**
- Take a case history and carry out medical examination(s) of the child/young person.
- Arrange appropriate investigations to aid diagnosis.
- Prescribe treatment and/or medication where appropriate.
- Refer to other specialists/professionals when necessary.
- Monitor growth and development of the child/young person.
- Look for signs of nutritional deficiencies in the child/young person.
- Jointly monitor the safety of the child’s/young person’s feeding regime and lead advice given accordingly.
- Work in partnership with the child/young person, family and other professionals involved to ensure the child/young person and family have the best treatment and support.

**Speech and Language Therapists:**
- Provide specialised assessment (which may include objective assessment methods) of children/young people having or suspected of having dysphagia.
- Consider safety, nutrition and hydration issues alongside the desire for developmental progress, with families and other professionals involved.
- Provide advice, strategies and guidance for families, staff and relevant agencies (jointly with other professionals involved).
- Liaise with school senior management and other education staff regarding information about eating and drinking requirements in the educational setting, and advise on implementing guidance.
- Support families and staff in making mealtimes safe and pleasurable.
- Jointly support families, alongside other professionals involved, in choosing between a number of feeding options and strategies when safe oral feeding is not possible.
- Review the eating and drinking guidelines provided and the progress of the child/young person on a regular basis.
- Be involved in the provision of training to all staff who feed children/young people, jointly with other professionals as appropriate.
- Bring to the attention of relevant other professionals concerns regarding the safety or health of individual children/young person as necessary.
Appendix 5: Education’s Roles and Responsibilities Summary

**Educational Psychologists:**
- Assist front-line workers in school/setting to understanding the implications of working with a child/young person with feeding difficulties and the impact upon their eating behaviours.
- Assist front-line workers to reduce any anxieties exhibited by the child/young person during feeding times.
- Assist front-line workers to recognise any additional barriers the school/setting may experience during feeding times and enable them to develop more positive feeding routines.
- Advise, front-line workers regarding any other learning difficulties and/or disabilities the child/young person may demonstrate.

**Special Educational Needs Casework Officers:**
- Ensure that information relating to a child's/young person’s feeding difficulties are specified accurately and in sufficient detail within the child’s Statement of Special Educational Needs and/or record.
- Monitor through consideration of annual review documentation whether the child’s/young person’s feeding difficulties are either lessening or gaining in severity and amending the Statement of Special Educational Needs and/or record as appropriate in response to the reports of the child’s current level of difficulty.

**Headteachers and/or SENCO**
- Ensure that all school staff have an awareness of the child’s/young person’s feeding difficulties and that staff directly involved in supporting the implementation of the child’s/young person’s MDT feeding plan are confident in doing this following the provision of necessary training.
- Ensure all MDT feeding plans are easily assessable for applicable staff.
- Liaise regularly with other professionals to seek advice and support as needed to ensure that the MDT feeding plan is implemented (as successfully as possible) to maximise the child’s/young person’s safety in obtaining a healthy and nutritional diet.
- Ensure current MDT feeding plans are maintained (as part of the child’s/young person’s record), regularly reviewed, amended and updated.

**Learning Support Assistants**
- Attend any training deemed necessary to support a child/young person with feeding difficulties.
- Exactly follow the guidance within the child's/young person’s MDT feeding plan.
- Deliver support sensitively (giving one to one support where necessary) to help the child/young person cope with any fears and/or anxieties they may have.
- Accurate records of a child's/young person’s food and fluid intake to be kept if applicable i.e. any refusal of food and/or fluid.
- Create an appropriate feeding environment based upon the child’s/young person’s individual needs to promote a safe and enjoyable mealtime.
- All necessary equipment will be kept separately from all other equipment/implements in the school dining area. It will be kept clean at all times and will be checked regularly to ensure it is fit for purpose.
Appendix 6: Social Care’s Roles and Responsibilities Per Setting Summary

Children’s Residential Care:
- To liaise with all other professionals, the family and child/young person (where appropriate) to gather all information relating to the child/young person to ascertain the child’s/young person’s level of need.
- To develop in conjunction with other professionals, the family, child/young person, and others (who have detailed knowledge of the child/young person) a MDT feeding plan which includes eating and drinking guidelines, a risk assessment and a daily care plan.
- To ensure that all staff groups working at the home receive training that will be refreshed and updated within appropriate timescales. Training will be multi-agency and cover all aspects of dysphagia and enteral feeding.
- Training will be designed to ensure staff meet the individual needs of all children/young people and that staff are competent and confident in using the taught techniques.
- Managers of the home will ensure that accurate records are maintained in relation to each child/young person and the plans for the child/young person are regularly reviewed, amended and updated.
- Managers of the home will liaise regularly with other professionals to seek advice and support as needed to ensure that a healthy and nutritional diet is maintained.
- Create an appropriate feeding environment based upon the child's/young person’s individual needs to promote a safe and enjoyable mealtime.
- Workers will work sensitively giving one to one support where necessary to help the child/young person cope with any fears and/or anxieties they may have.
- Workers at the home will maintain close contact with the families/carers of children/young people in order that consistency is maintained and to exchange information and provide support.
- A protocol will be available in the home to guide staff should there be any change in the child's/young person’s health and/or behaviour which could cause immediate concern.
- A worker with an up to date qualification in first aid will work on every shift.
- All necessary equipment will be kept separately from all other kitchen paraphernalia in the house. It will be kept clean at all times and will be checked regularly to ensure good order.
- Accurate records of a child’s/young person’s food and fluid intake to be kept if applicable i.e. any refusal of food and/or fluid.

Children’s Family Placement:
- To liaise with all other professionals, the family and child/young person (where appropriate) to gather all information relating to the child/young person to ascertain the child’s/young person’s level of need.
- To ensure that the carer receives training that will be reviewed and updated within appropriate timescales. Training will be multi-agency and cover all aspects of dysphagia and enteral feeding.
- To develop in conjunction with other professionals, the family, child/young person, and others (who have detailed knowledge of the child/young person) a MDT feeding plan which includes eating and drinking guidelines, a risk assessment and a daily care plan.
- Identify a suitable carer and ensure their agreement to undertake the intervention.
- Request for training of the carer prior to the child/young person being placed and confirmation of competency.
The carer will ensure that accurate records are maintained in relation to the child/young person and the plans for the child/young person are regularly reviewed, amended and updated.

The carer will liaise regularly with other professionals to seek advice and support as needed to ensure that a healthy and nutritional diet is maintained.

The carer will work sensitively giving one to one support where necessary to help the child/young person cope with any fears and/or anxieties they may have.

The carer will maintain close contact with the families/carers of children/young people in order that consistency is maintained and to exchange information and provide support.

A protocol will be available in the home to guide the carer should there be any change in the child’s/young person’s health and/or behaviour which could cause immediate concern.

All necessary equipment will be kept separately from all other kitchen equipment in the house. It will be kept clean at all times and will be checked regularly/with appropriate maintenance to ensure good order.

Accurate records of a child’s/young person’s food and fluid intake to be kept if applicable i.e. any refusal of food and/or fluid.

The carer will let their supervising social worker know if there are any concerns or changes to the procedures they have been trained in with regards to the child/young person.

**Children’s Short Breaks Individual Support Workers:**

- Child’s/young person’s social worker to liaise with all other professionals, the family and child/young person (where appropriate) to gather all information relating to the child/young person to ascertain the child’s/young person’s level of need.

- The child’s/young person’s social worker will ensure that the individual support worker receives training that will be reviewed and updated within appropriate timescales. Training will be multi-agency and cover all aspects of dysphagia and enteral feeding.

- The child’s/young person’s social worker will identify a suitable individual support worker and ensure their agreement to undertake the intervention.

- Request for training of the individual support worker prior to the child/young person being introduced and confirmation of competency.

- The individual support worker will liaise regularly with other professionals to seek advice and support as needed.

- The individual support worker will work sensitively giving one to one support where necessary to help the child/young person cope with any fears and/or anxieties they may have.

- A protocol will be available to guide the individual support worker should there be any change in the child’s/young person’s health or behaviour which could cause immediate concern.

- Accurate records of a child’s/young person’s food and fluid intake to be kept if applicable i.e. any refusal of food and/or fluid.

- The individual support worker will inform the child’s/young person’s social worker if there are any concerns or changes to the procedures they have been trained in with regards to the child/young person. Additional training can be arranged via the social worker.
Multi-agency meeting (in consultation with parent/carer and/or child/young person) involving relevant professionals and setting management.

Individual MDT feeding plan with timescales developed and agreed.

Copies of the MDT feeding plan sent to the family, relevant professionals and setting management.

Staff to jointly ensure appropriate equipment/utensils are in place upon arrival.

Setting staff to determine an easily accessible location for the MDT feeding plan to be kept.

Staff responsible for feeding/supporting the child/young person are in place.

Staff responsible for feeding/supporting to receive the appropriate level of training - initiated by the setting manager and/or individual.

Staff responsible for feeding/supporting to receive copy of the MDT feeding plan from the setting manager.

*MDT: Multidisciplinary Team*
Appendix 8: Example MDT Feeding Plan

Multidisciplinary Feeding Plan

Child’s/Young Person’s Name: ____________________________  Child’s/Young Person’s D.O.B.: ____________________________

Plan Developed By: ____________________________  Date: ____________________________

Professionals Involved

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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Feeding Plan Summary

Positioning/Environment:

Food/Texture:

Drinks:

Equipment:

Communication

Things to look out for:

I (Plan developer) have explained the above multidisciplinary feeding plan to the setting manager.

Signed: ____________________________  Date: ____________________________

I (Setting Manager) have read and understood this multidisciplinary feeding plan and will ensure it is implemented by the setting staff.

Signed: ____________________________  Setting Manager  Date: ____________________________
Aspiration is when food or drink goes “down the wrong way” i.e. into the lungs. This can be silent – with no cough. As this is a serious risk to health, everyone involved with the child’s feeding should be aware of the signs.

~ Loss or change of colour, e.g. face goes pale / grey / blue / reddens.

~ Eyes watering or increased blinking

~ Facial expressions or grimacing, indicating anxiety / distress

~ Coughing

~ Gagging

~ Difficulty or change in rate of breathing

~ Breathing becomes noisy

~ Repeated attempts to clear throat

~ Wet / gurgly / rattly voice quality

~ Runny nose and increased drooling

~ Hiccupping

~ Lips/nail beds tinged blue

~ Frequent chest infections/ pneumonia

IF YOU THINK A PUPIL MAY BE ASPIRATING...

- STOP giving food / drink
- Give them time to recover
- Seek help if still concerned – call first aid trained staff
- Report any concerns to the class teacher
Please ensure that Alisha is sitting in an upright position and is comfortable in her chair in order to provide maximum safety and to optimise Alisha’s eating and drinking skills.

- It is important that Alisha’s hips and knees are at a 90 degree angle at hips and knees (see picture on left) and feet supported on her foot rest.
- Alisha’s arms should be supported in a relaxed position on the tray in front of her chair.

Alisha uses a doidy cup for all her drinks. This cup allows Alisha to take small, controlled sips without needing to tip the cup.

Encourage Alisha to take small sips from her cup, to allow her time to manage the liquid in her mouth and swallow this, before taking another sip.

Please contact me if you have any questions or concerns about Alisha’s eating and/or drinking:

Name of Speech and Language Therapist
Contact telephone number

Speech and Language Therapy
St. Mary’s Hospital
Green Hill Road
Leeds, LS12 3QE
Appendix 10: Implementation & Monitoring While the Child/Young Person is in the Setting

*MDT: Multidisciplinary Team

- MDT feeding plan has NOT been successfully implemented and/or is NOT being followed by the staff feeding/supporting the child/young person.
  - Setting management to provide a copy of the MDT feeding plan to the feeding/supporting staff and to monitor if the plan is understood and implemented.
  - If the plan is NOT implemented:
    - The feeding/supporting member of staff to be appropriately managed through agency specific procedures.
  - If implementation is successful:
    - MDT review of the child's/young person's feeding plan, needs and skills to be reviewed within the agreed timescales (This maybe in conjunction with existing reviews).
- MDT feeding plan being followed by the staff feeding/supporting the child/young person.
- MDT feeding plan revised as necessary. Copies of the revised MDT feeding plan sent to the family, relevant professionals and setting management.
- ONLY appropriately trained staff can conduct the feeding.
- If further training is required the setting manager and/or individual is to initiate training via the relevant health professional(s) (refer to section 8.2 of the guideline).
Appendix 11: Guideline Audit Proposal

Adherence to the Inter-Agency Guideline for the Assessment and Management of Children/Young People with Dysphagia (Complex Feeding) in Community and Education Settings within Leeds

- **Audit Frequency:** Every 3 years
- **Audit Initiated By:** The Children’s Therapy Head of Service or equivalent
- **Audit Participation:** Health, education, social care and the private/voluntary sector.
- **Background:** In Leeds, there are approximately 250 children/young people with significant feeding difficulties; the vast majority of these are disabled (NHSLCH, 2008). In Leeds most disabled children/young people of school age are educated in “mainstream” settings as part of Leeds inclusion strategy. Those children/young people who are unable to feed themselves are often fed by teaching assistants employed by the child’s/young person’s school. Teaching assistants work under the supervision of the class teacher with advice from the special education needs coordinator (SENCO), educational psychologist and speech and language therapist. Social care and the private and voluntary sector may be involved if the child/young person has pre-school education, private school education or short break care. Following an incident in 2007, NHS Leeds has identified dysphagia as a high risk area. An interagency guideline has been developed to establish a consistent, cohesive approach between health, education, social care and the private/voluntary sector to manage the risks associated with moderate, major and/or profound dysphagia.
- **Gold standard:** All the children/young people with moderate, major and/or profound dysphagia in Leeds should have a multidisciplinary feeding plan as per the guideline (NHSLCH, 2010).
- **Objectives:** To ensure that children/young people with moderate, major and/or profound dysphagia receive:
  1. A MDT assessment when their feeding difficulty is recognised and/or alters.
  2. A timely, MDT review of their growth and feeding routine.
  3. An agreed MDT feeding plan for which there is multi-agency responsibility.
- **Estimated number in the audit sample:** 25 children (10% of total 250 children) with moderate, major and/or profound dysphagia.
- **Estimated start date:** September 2013
- **Estimated completion date:** December 2013
- **References:**

**Guideline Consultation Responses**

Complete this template when receiving comments at various draft stages of the Guideline.

<table>
<thead>
<tr>
<th>Responder (including job titles and organisation)</th>
<th>Comment and Date</th>
<th>Response from Author</th>
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<tbody>
<tr>
<td><strong>ALL</strong></td>
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<td>When appropriate comments added.</td>
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<tr>
<td>Disabled Children with Feeding Difficulties Meetings held frequency throughout the guideline writing process.</td>
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<td>When appropriate comments added.</td>
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<tr>
<td><strong>Liz Franklin, Speech and Language Therapist, NHSLCH</strong></td>
<td>8.7.2010:</td>
<td>When appropriate comments added.</td>
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<tr>
<td>1) <strong>Purpose:</strong> Fine</td>
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<td>2) <strong>Scope:</strong> add “Family Outreach Workers” to Social Care/Private &amp; Voluntary Care section?</td>
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<td>5) <strong>Objectives:</strong> I know we discussed these last time, but on reflection I feel the phrase “manage the risks associated with inadequate nutrition and aspiration for…” does not capture all aspects necessary, and therefore something more general like “Manage the risks and improve the outcome for…” might be better.</td>
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<td>6) <strong>Client Group – inclusion:</strong> “enrolled in further education” better than “on an academic course”?</td>
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<td>7) <strong>Exclusion:</strong> Fine</td>
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<td>9) <strong>Training Needs:</strong> Discussed with Kate this week. Do we actually need statements on what our training needs are? Should definitely include training needs of Education/Social Care Staff who are involved if feeding these children – maybe a general statement eg “Basic MDT Training covering all relevant aspects of dysphagia” organised and led by Health, with updates 1-2 yearly?</td>
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<td>10) <strong>Body of Guideline:</strong> Have discussed with Kate sections 10.2.5 and 10.3.4. I’m not sure why SLT specific information from our standards document needs to be included here if nobody else’s on the MDT are. We have already written our roles and responsibilities, and some of these points should apply to everyone working with the child (eg checking for allergies). Similarly with Risk Assessments. To put SLT-only further roles and responsibilities in this document seems to only reinforce the perception that it’s really the SLTs problem to sort out – whilst this document is supposed to help us move away from this view. Also 10.3.1 needs amending if we do amend objective 2 (see point 5)</td>
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<td>11) <strong>Equipment and Resources:</strong> Specialist equipment may be required for children. This may include seating equipment, medical equipment, specialist utensils, use of thickeners for texture modification, etc. NB do we need to say who is responsible for providing this?</td>
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<td>12) <strong>Risk matrix</strong> – can I reiterate this is what SLTs only use, and is not in general use across PCT. We also use an Equipment Register in case of product recalls.</td>
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**Liz Franklin, Speech and Language Therapist, NHSLCH**

1) **Paediatricians:**
   - Take a case history and carry out medical examination(s) of the child
   - Arrange appropriate investigations to aid diagnosis
   - Prescribe treatment and/or medication where appropriate
   - Refer to other specialists/professionals when necessary
   - Monitor growth and development of the child
   - Look for signs of nutritional deficiencies in the child
   - Jointly monitor the safety of the child’s feeding regime and lead advice given accordingly
   - Work in partnership with the child, family and other professionals involved to ensure the child and family have the best treatment and support

2) **Speech and Language Therapists:**
   - Provide specialised assessment (which may include objective assessment methods) of children having or suspected of having dysphagia
   - Consider safety, nutrition and hydration issues alongside the desire for developmental progress, with families and other professionals involved
   - Provide advice, strategies and guidance for families, staff and relevant others, jointly with other professionals involved
   - Liaise with school Senior Management and other Education staff regarding information about eating and drinking requirements in the educational setting, and advise on implementing guidance
   - Support families and staff in making mealtimes safe and pleasurable
   - Jointly support families, alongside other professionals involved, in choosing between a number of feeding options and strategies when safe oral feeding is no longer possible.
Review the eating and drinking guidelines provided, and the progress of the child, on a regular basis.

- Be involved in the provision of training to all staff who feed children, jointly with other professionals as appropriate.
- Bring to the attention of relevant other professionals concerns regarding the safety or health of individual children as necessary.

### 3) Dieticians:

- Identify children at risk of dysphagia and refer them to the appropriate services.
- Assess children and advise on suitable diet, in conjunction with SLT colleagues, to maximise safety and ensure eating and drinking remains an enjoyable and social experience.
- Advise on texture modification, jointly with SLTs.
- Ensure that an adequate diet is taken to support appropriate growth and to provide essential nutrients and to advise on suitable fortification and supplementation of diet where necessary.
- Advise on fluid intake and support the provision of thickened fluids where necessary.
- Monitor and review both orally and enterally fed children using a variety of tools (including anthropometry, biochemistry and multidisciplinary assessment).
- Advise, initiate and support joint decision making regarding enteral feeding.
- Assess requirements and prescribe enteral feeding regimens for children where necessary.
- Act as key link with the Home Enteral Feeding Service provider and direct this provision.
- Support multiagency and multidisciplinary training regarding all aspects of dysphagia and enteral feeding.

### 4) Clinical Psychologists:

- Recognise the anxiety that having a child with feeding difficulties can cause parents and carers.
- Assist families in understanding the pressure this anxiety can cause and the impact of this on the child’s eating behaviours.
- Help families identify the root of this anxiety, and understand its beginnings and the role it has in the child’s current feeding difficulties.
- Assist in reducing any anxieties exhibited by the child.
- Advise jointly with other professionals on any level of developmental delay the child may show, and the impact of these on feeding development.
- Help families understand sensory developmental processes, jointly with other professionals, and the impact of disruption to these on feeding development where necessary.
- Help families recognise any difficulties or concerns with eating they may have themselves and how these may impact on the child.
- Assist in enabling families to develop healthier feeding routines and more relaxed, enjoyable mealtimes.

---

**David Cundall, Community Paediatrician, NHSLCH**

19.7.2010: Feedback from the Paediatricians:

- How often do we monitor growth - I said it’s case-dependent
- How do we monitor growth - literature suggests that some conventional measures less appropriate for this population - I don’t think we need to go into detail for this guideline but I’ll flag it up as something that needs bit more work outside the guideline process.

---

**David Cundall, Community Paediatrician, NHSLCH**

21.7.2010

1. **Purpose**: agreed
2. **Scope**: in private/voluntary sector throughout. As this group is quite large does anyone know of a rep who could be involved in the development of the guideline and implementation? All: Which groups would fall into the private/voluntary sector. MENCAP, Weekenders, Carers Leeds, People in Action, SCOPE, Parent Power, Barbara will know about all the short break providers

5. **Objectives**: Changed the word agencies to professional groups. May not be ideal – teaching assistants/dinner ladies might not be regarded as professionals but maybe everyone is now. Could we use “people” instead

8. **Multidisciplinary Feeding Plan Implementation**

- This section has altered the most and I would greatly appreciate everyone’s comments.
- I have slight misgivings about the word “catastrophic” – fully agree with S&LT colleagues that we need strong words to emphasise just how dangerous this situation can be, but I’m worried that it’ll frighten our risk managers too much. Can we just stick to “profound” – I’ll defer to Liz’s opinion on this one. Whilst I think about it, are we keeping LTHT S&LT colleagues in the loop as we progress this…?

- 8.2: Could everyone look through the four different training levels to see if I have captured things correctly or if there are things which should be added.
I've therefore inserted a copy of these sections here so you can work on it directly

8.2 Staff Requirements/Training Needs

8.2.1 Level 1: Guidance Awareness

Training Synopsis: A general update

Staffing Groups: Health, Education and Social Care staff groups outlined in section 2 whose role may involve working with/caring for a child with moderate, major and/or profound dysphagia but who are not directly involved in the assessment or provision of feeding.

Training Provider: Health, Education and Social Care line managers to cascade information.

Training Frequency: Upon initial release of the guideline and subsequently every 2 years when the guideline is reviewed.

8.2.2 Level 2: Manager Accountability Training

Training Synopsis: Training focused around reviewing the purpose and function of an MDT feeding plan, identifying which children would benefit from a plan, how plans should be recorded and reviewed, MDT roles and responsibilities, etc.

Staffing Groups: For those staff responsible for signing off/approving multidisciplinary team (MDT) feeding plans (refer to Table 1 for further clarity).

Training Provider: Healthcare professional (Do we need to be more specific) I don't think so

Training Frequency: For all new starters. Refresher training upon request.

8.2.3 Level 3: Multidisciplinary Practitioner Training

Staffing Groups: For all staff involved in the feeding assessment and/or monitoring process (refer to see Table 1 for further clarity).

Training Provider: Healthcare professional (Do we need to be more specific) should we insist on the training being multi-disciplinary?

Training Frequency: Training to be completed as a one off upon initial release of the guideline and subsequently for all new starters. Refresher training upon request and every two years when guideline reviewed.

8.2.4 Level 4: Competency Training

Staffing Groups: For all staff involved in feeding a child with moderate, major and/or profound dysphagia (refer to see Table 1 for further clarity).

Training Provider: Healthcare professional (Do we need to be more specific) S&LT and other trainers who have been trained for this task by S&LTs?

Training Frequency: For all new starters. The MDT feeding plan for a child/young person which the member of staff is involved with will drive the training i.e. if there is no change to the plan leading up to or during the annual review training may not be required. However, if the plan changes and/or the needs of the child change retraining will be necessary. completed upon discretion of the paediatrician???? Is this correct? no, not the paediatrician. Refresher training upon request.

Liz Franklin,
Speech and Language Therapist,
NHSLCH

27.7.2010

1. Purpose: agreed

2. Scope: Should also say all staff in private nursery/crèche settings

5. Objectives: Or maybe “staff” or “staff groups”?

6. Client Group – Inclusion: “children and young people who reside in Leeds and/or have a Leeds GP, This probably does encompass all our cases effectively

7. Client Group – Exclusion: Confirmed fine

8. Multidisciplinary Feeding Plan Implementation: Think it’s fine to omit the word “catastrophic” from this document, given who it’s for. Yes, David, don’t worry – have been liaising with Jo Gallagher and also SILC SLTs throughout!

8.2.3 Level 3: Multidisciplinary Practitioner Training: Ideal – could say “relevant specialist healthcare professional(s)” Training Frequency: or if need has been identified and every two years when guideline reviewed.

8.2.4 Level 4: Competency Training: No, other staff would not nec. have been trained by SLTs. Again, “relevant specialist healthcare professionals” and could say “likely to include SLT”

8.4.1 Implementation Prior to the Child’s Arrival in the Setting

- Multiagency meeting involving relevant health professionals and setting management, to develop feeding plan, in consultation with parents/carers and/or child/ young person
- Copies of plan sent to family, relevant health and social care professionals, and setting staff. Setting managers to ensure plan kept in easily accessible location
- Staff who will feed or support the child in self-feeding appointed in place, and receive copy of feeding plan from their managers
- Staff who will feed or support self-feeding to receive appropriate training, at request of their managers
- All agencies to ensure appropriate equipment and utensils in place

8.4.2 Implementation Once Child is attending Setting

- Feeding plan to be easily accessible and implemented by staff feeding child or supporting self-feeding
- Following of plan to be monitored by setting managers and by visiting health or social care staff as appropriate
- Feeding of child or supporting of self-feeding only to be conducted by appropriately trained staff
### Setting staff/managers to request further training when needed
- Health/Social care staff to highlight any perceived training need with setting staff/managers
- Feeding plan to be reviewed at least annually and revised as necessary

### 3.8.2010 Dysphagia
#### 10.2.4 Roles and Responsibilities: Social Care

**Children's Residential Care**
- To liaise with all other professionals, the family, and child, where appropriate, to gather all information relating to the child to ascertain the child's level of need.
- To develop in conjunction with other professionals, the family, child, and others who have detailed knowledge of the child, a health care plan, a feeding plan which includes eating and drinking guidelines, a risk assessment and a daily care plan.
- To ensure that all staff working at the home receive training that will be refreshed and updated within appropriate timescales. Training will be multi agency and cover all aspects of dysphagia and enteral feeding.
- Training will be designed to ensure staff meet the individual needs of all children and that staff are competent and confident in using the taught techniques.
- Managers of the home will maintain accurate records in relation to each child and ensure that the plans for the child are reviewed on a regular basis and amended and updated as necessary.
- Managers of the home will ensure that regular dialogue is maintained with other professionals and advice and support is sought in order to ensure that the child has a healthy and nutritional diet.
- Workers at the home will maintain close contact with the families and carers of children in order that consistency is maintained and to exchange information and provide support.
- A protocol will be available in the home to guide staff should there be any change in the child’s health or behaviour which cause immediate concern.
- A worker qualified in first aid will work on every shift.
- Feeding equipment will be kept separately from all other equipment in the house. Feeding equipment will be kept sterile at all times and will be checked regularly to maintain good order.
- Accurate records of a child's food and fluid intake will be kept. Any refusal of food or fluid will be noted.
- Workers will ensure that they work in a sensitive manner and that the child is given 1:1 support to help them with any fears or anxieties they may have.
- Include all children in mealtimes where this is possible and help them to enjoy this as a social time.

### 3.8.2010 Dysphagia
#### 10.2.4 Roles and Responsibilities: Social Care

**Staff Responsible for Feeding: Residential workers. Family Placement Carers. Individual support workers.
Staff Responsible for Monitoring/Reviews: Residential unit managers. Family Placement managers. Social care team managers**

Manager Accountability Training: Residential Unit Managers. Family Placement managers. Social care team managers
Practitioner Training: Residential care workers. Family Placement carers. Individual support workers

### 16.8.2010 Appendix VI: Social Care's Roles and Responsibilities Summary

**Children's Residential Care**
- To liaise with all other professionals, the family, and child, where appropriate, to gather all information relating to the child to ascertain the child’s level of need.
- To develop in conjunction with other professionals, the family, child, and others who have detailed knowledge of the child, a health care plan, a feeding plan which includes eating and drinking guidelines, a risk assessment and a daily care plan.
- To ensure that all staff working at the home receive training that will be refreshed and updated within appropriate timescales. Training will be multi agency and cover all aspects of dysphagia and enteral feeding.
- Training will be designed to ensure staff meet the individual needs of all children and that staff are competent and confident in using the taught techniques.
- Managers of the home will ensure that accurate records are maintained in relation to each child and the plans for the child are regularly reviewed, amended and updated.
- Managers of the home will liaise regularly with other professionals to seek advice and support as needed to ensure that a healthy and nutritional diet is maintained.
- Include all children in mealtimes wherever possible and help them all to enjoy this as a social time.
- Workers will work sensitively giving 1:1 support where necessary to help the child cope with any fears or anxieties they may have.
- Workers at the home will maintain close contact with the families and carers of children in order that consistency is maintained and to exchange information and provide support.
- A protocol will be available in the home to guide staff should there be any change in the child’s health or behaviour which cause immediate concern.

---

When appropriate comments added.
A worker with an up to date qualification in first aid will work on every shift.

All necessary equipment will be kept separately from all other kitchen paraphernalia in the house. It will be kept sterile at all times and will be checked regularly to ensure good order.

Accurate records of a child’s food and fluid intake will be kept. Any refusal of food or fluid will be noted.

**Children’s Family Placement**

- To liaise with all other professionals, the family, and child, where appropriate, to gather all information relating to the child to ascertain the child’s level of need.
- To ensure that the carer receives training that will be reviewed and updated within appropriate timescales. Training will be multi agency and cover all aspects of dysphagia and enteral feeding.
- Identify a suitable carer and ensure their agreement to undertake the intervention.
- Request for training of the carer prior to the child being placed and confirmation of competency.
- To develop in conjunction with other professionals, the family, child, and others who have detailed knowledge of the child, a health care plan, a feeding plan which includes eating and drinking guidelines, a risk assessment and a daily care plan.
- The carer will ensure that accurate records are maintained in relation to the child and the plans for the child are regularly reviewed, amended and updated.
- The carer will liaise regularly with other professionals to seek advice and support as needed to ensure that a healthy and nutritional diet is maintained.
- The carer will work sensitively giving 1:1 support where necessary to help the child cope with any fears or anxieties they may have.
- The carer will maintain close contact with the families and carers of children in order that consistency is maintained and to exchange information and provide support.
- A protocol will be available in the home to guide the carer should there be any change in the child’s health or behaviour which cause immediate concern.
- All necessary equipment will be kept separately from all other kitchen equipment in the house. It will be kept sterile at all times and will be checked regularly with appropriate maintenance to ensure good order.
- Accurate records of a child’s food and fluid intake will be kept. Any refusal of food or fluid will be noted.
- The carer will let their supervising social worker know if there are any concerns or changes to the procedure they have been trained in respect of the child.

**Children’s Short Breaks Individual Support Workers**

- Child’s social worker will liaise with all other professionals, the family, and child, where appropriate, to gather all information relating to the child to ascertain the child’s level of need.
- The child’s social worker will ensure that the individual support worker receives training that will be reviewed and updated within appropriate timescales. Training will be multi agency and cover all aspects of dysphagia and enteral feeding.
- The child’s social worker will identify a suitable individual support worker and ensure their agreement to undertake the intervention.
- Request for training of the individual support worker prior to the child being introduced and confirmation of competency.
- The individual support worker will liaise regularly with other professionals to seek advice and support as needed.
- The individual support worker will work sensitively giving 1:1 support where necessary to help the child cope with any fears or anxieties they may have.
- A protocol will be available to guide the individual support worker should there be any change in the child’s health or behaviour which cause immediate concern.
- Accurate records of a child’s food and fluid intake will be kept. Any refusal of food or fluid will be noted.
- The individual support worker will inform the child’s social worker know if there are any concerns or changes to the procedure they have been trained in respect of the child. Additional training can be arranged via the social worker.

David Cundall,
Community Paediatrician,
NHSLCH

30.8.2010

I have a few minor comments/corrections:

8.2.1 thru to 8.2.3
we refer to Staffing Groups - I think Staff Groups reads better
8.3.1 second bullet point
we refer to patients - I think we should stick to child's or, possibly child's/young person's
8.4
in the tabulated version of the flowcharts we refer to optimum feeding input
can we delete ‘input’ or does it change its meaning if we do? If it's OK optimum feeding reads better
9. Equipment
9.1 second line add an apostrophe to agencies’
11.2 audit proposal
line 2 should be dysphagia not dysphasia
In the reference abstracts 10b the Pediatrics article is still in capitals. It will be easier to read if it is lower case. 11b 3 and also 12b I would prefer 'community paediatricians' to 'Medics' in both cases.

Andrea Robinson, Head of Service, Special Educational Needs, Statutory Assessment and Provision, Education Leeds

<table>
<thead>
<tr>
<th>8.9.2010 Appendix V: Education’s Roles and Responsibilities Summary</th>
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</thead>
<tbody>
<tr>
<td><strong>Educational Psychologists:</strong></td>
</tr>
<tr>
<td>• Assist front-line workers in school/setting to understanding the implications of having a child with feeding difficulties (and the impact upon their eating behaviours)</td>
</tr>
<tr>
<td>• Assist front-line workers to reduce any anxieties exhibited by the child at feeding times.</td>
</tr>
<tr>
<td>• Assist front-line workers to recognise any additional barriers the school/setting may experience at feeding times, and enable them to develop more positive feeding routines.</td>
</tr>
<tr>
<td>• Advise, front-line workers regarding any other learning difficulties or disabilities the child may demonstrate.</td>
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<tr>
<th><strong>Special Educational Needs Casework Officers:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ensure that information relating to a child’s feeding difficulties are specified accurately and in sufficient detail within the child’s Statement of Special Educational Needs.</td>
</tr>
<tr>
<td>• Monitor through consideration of Annual Review Documentation whether the child’s feeding difficulties are either lessening or gaining in severity and amending the Statement of Special Educational Needs as appropriate in response to the reports of the child’s current level of difficulty.</td>
</tr>
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<thead>
<tr>
<th><strong>Headteachers and/or SENCO</strong></th>
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<tbody>
<tr>
<td>• Ensure that all staff in school have an awareness of the child’s feeding difficulties and that staff directly involved in supporting the implementation of the child’s feeding plan are confident in doing this following the provision of necessary training.</td>
</tr>
<tr>
<td>• Liaise regularly with other professionals to seek advice and support as needed to ensure that the feeding plan is implemented as successfully as possible in order for the child to maximise the child’s safety in obtaining a healthy and nutritional diet.</td>
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<tr>
<th><strong>Learning Support Assistants</strong></th>
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<tr>
<td>• Attend any training deemed necessary to enable them to support a child with feeding difficulties.</td>
</tr>
<tr>
<td>• Follow exactly the guidance within the child’s feeding plan.</td>
</tr>
<tr>
<td>• Deliver support sensitively giving one to one support where necessary to help the child cope with any fears or anxieties they may have.</td>
</tr>
<tr>
<td>• Accurate records of a child’s food and fluid intake will be kept. Any refusal of food or fluid will be noted.</td>
</tr>
<tr>
<td>• Include all children in mealtimes wherever possible and help them all to enjoy this as a social time.</td>
</tr>
<tr>
<td>• All necessary equipment will be kept separately from all other equipment/implements in the school dining area. It will be kept sterile at all times and will be checked regularly to ensure it is fit for purpose.</td>
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Kalyani Mulay, Community Paediatrician, NHSLCH

<table>
<thead>
<tr>
<th>16.8.2010 Audit titleAdherence to the Inter-Agency Guideline for the Assessment and Management Of Children with Dysphagia (Swallowing Difficulties) in Leeds</th>
</tr>
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<tbody>
<tr>
<td><strong>Name of the persons undertaking the audit</strong></td>
</tr>
<tr>
<td>Kalyani Mulay</td>
</tr>
<tr>
<td>Liz Franklin</td>
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</tbody>
</table>

**Background**

In Leeds, there are approximately 250 children with significant feeding difficulties; the vast majority of these are disabled. In Leeds most disabled children of school age are educated in “mainstream” settings as part of Education Leeds inclusion strategy. Those children who are unable to feed themselves are often fed by teaching assistants employed by the child’s school. Teaching assistants work under the supervision of the class teacher with advice from the Special Education Needs Coordinator (SENCO), educational psychologist and speech and language therapist. Social Care and the private and voluntary sector may be involved if the child has pre-school education, private school education or short break care.

Following an incident in 2007, NHS Leeds has identified dysphagia as a high risk area. An interagency guideline has been developed to establish a consistent, cohesive approach between Health, Education and Social Care to manage the risks associated with moderate, major and/or profound dysphagia.

**Gold standard**

All the children with significant feeding difficulties in Leeds should have an interagency multidisciplinary feeding plan as per the guideline.³

**Objectives**

To ensure that children with significant feeding difficulties receive

- A multidisciplinary assessment, at the point at which their feeding difficulties are recognised. |
- Timely, multidisciplinary review of their growth and feeding routine. |
- A safe feeding plan for which there is inter-agency responsibility. |

Estimated number in the audit sample
25 children (10% of total 250 children) with moderate to severe feeding difficulties.

**Estimated start date**
August 2012

**Estimated completion date**
December 2012

**References:**
1. Inter-Agency Guideline for the Assessment and Management of children with dysphasia (Swallowing Difficulties) in Community and Education Settings within Leeds.

| Jen McAnuff, Clinical Specialist/Deputy Manager Occupational Therapy, NHSLCH | 10.9.2010

**Occupational Therapists:**
Be aware when a child receiving occupational therapy has / is suspected of having dysphagia and communicate with the MDT as appropriate.
Assess the child’s self-feeding and mealtime participation in home and education environments.
Identify factors about the child, their social, cultural and physical environments, and their mealtime activities that may be impacting on their self-feeding and mealtime participation.
Provide general advice to families on developing self-feeding skills and joining in at mealtimes.
Engage families and child where possible in goal-setting for self-feeding and mealtime participation in collaboration with the MDT and being aware of safety priorities.
Provide specific advice on established goals in collaboration with the MDT including positioning, sensory tolerance and processing, motor skills, visual support, routines, environmental distractions, time available, expectations and grading, and opportunities for self-feeding.
Assess for assistive technology to support safety, self-feeding and joining in at mealtimes e.g. seating and tables, adapted utensils or powered devices.
Contribute to established eating and drinking guidelines as appropriate.
Contribute to multidisciplinary feeding training as appropriate.

When appropriate comments added
Complete details in boxes provided

Name of Guideline: Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Complex Feeding) in Community and Education Settings within Leeds

Person presenting
1. Liz Franklin, Speech and Language Therapist
2. David Cundall, Community Paediatrician
3. Kalyani Mulay, Community Paediatrician
4. Katherine Slagle, Head of Service Children’s Therapy

Key: Y = Yes, N = No, ? = don’t know

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<tr>
<th>Criterion</th>
<th>Y</th>
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<th>Comment</th>
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<tr>
<td>Source</td>
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<tr>
<td>Is the authorship clear?</td>
<td>Y</td>
<td></td>
<td>Page 1: Authorship Page 26: Appendix III: Examples of and Contact Information for Multi-agency Staff Groups Involved in Guideline Dissemination and Training</td>
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<th>Criterion</th>
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<th>For C-GaP use only</th>
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<tbody>
<tr>
<td>Has external sponsorship been used? If so does this comply with the Trust’s policy for sponsorship?</td>
<td></td>
<td>N</td>
<td></td>
<td>Page 4: Following an incident in 2007, NHS Leeds identified dysphagia as a high risk area. The Leeds Disabled Children’s Programme Board has subsequently given its approval to develop an inter-agency guideline.</td>
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<tr>
<td>Purpose</td>
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<tr>
<td>Is purpose clearly stated?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Page 4: Section 1 = Purpose. Clear description in paragraph 6 of the purpose.</td>
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<tr>
<td>Is the patient population or medical condition/situation to which the document applies clear?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Page 4: Purpose Page 6: Inclusion Criteria (6.1-6.4) Pages 6-7 Exclusion Criteria (7.1-7.4) Page 7: 8.1 Dysphagia Definitions</td>
<td></td>
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<tr>
<td>Are the conditions or populations, which exclude patients from the guideline (e.g. children or patients with heart disease), clearly stated?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Page 4: Purpose Page 6: Inclusion Criteria (6.1-6.4) Pages 6-7 Exclusion Criteria (7.1-7.4) Page 7: 8.1 Dysphagia Definitions Pages 24-25: Appendix II: Paediatric Speech and Language Therapy Dysphagia Risk Matrix</td>
<td></td>
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<tr>
<td>Is the professional group to whom the guideline is intended clearly stated?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Pages 4-5: Scope Pages 7-8: 8.2 Staff Requirements/Training Needs Page 8: 8.3 Roles and Responsibilities Page 26: Appendix III: Examples of and Contact Information for Multi-agency Staff Groups Involved in Guideline Dissemination and Training Pages 27-28: Appendix IV: Health’s Roles and Responsibilities Summary Page 29: Appendix V: Education’s Roles and Responsibilities Summary Pages 30-31: Appendix VI: Social Care’s Roles and Responsibilities Summary Per Setting Summary</td>
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<td>Evidence base</td>
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<tr>
<td>Does the document include a clear description of the sources of information used to select evidence?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Page 12: References Pages 13-23: Appendix I: Equality Impact Assessment, 10a, 10b Pages 24-25: Appendix II: Paediatric Speech and Language Therapy Dysphagia Risk Matrix</td>
<td></td>
</tr>
<tr>
<td>Are these sources adequate i.e. is the literature search described and are the sources appropriate/legitimate?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Page 5: 3.2 Equality Impact Monitoring (pre-audit explanation) Pages 13-23: Appendix I: Equality Impact Assessment (Pro-forma for</td>
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</table>
identifying monitoring requirement of a policy/strategy/project or service): Prior to this guideline being developed an audit was conducted against the proposed guideline standards. A re-audit against these standards will be conducted by health (joint responsibility of the senior Speech and Language Therapist with responsibility for dysphagia and the paediatrician who leads on disability) with input from education, social care and ideally the private/voluntary sector. The guideline will be reviewed every three years. Each time the guideline is reviewed a current literature search will be conducted, dysphagia specific incidents and complaints (from each agency) will be reviewed and service user feedback will be assessed.

This guideline is for a small cohort of patients in Leeds. The clinicians and teams involved in the development of the guideline are experts in their respective fields and understand the needs and health risks associated with this group of children/young people. The data used from the NHSLCH SLT database to accurately reflect the population.

### Development

<table>
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<tr>
<th>Criterion</th>
<th>Y</th>
<th>N</th>
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<th>Comment</th>
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<tbody>
<tr>
<td>Has the document been peer reviewed, either by an external expert or through consultation with key stakeholders?</td>
<td>Y</td>
<td></td>
<td></td>
<td>Consultation Period: 2 weeks (18.8.2010-2.9.2010). The guideline was sent to health, education, social care and voluntary/private sector colleagues to disseminate for consultation. This guideline was also distributed for comment by the C-Gap team. The guideline was also reviewed by the complex feeding guideline team.</td>
</tr>
<tr>
<td>If the document refers to medicines and/or prescribing, has it been considered by the Medicines Management Team – Contact Carolyn Nelson Head of Medicines Management (Provider Services) 0113 22 08536 <a href="mailto:carolyn.nelson@nhsleeds.nhs.uk">carolyn.nelson@nhsleeds.nhs.uk</a></td>
<td>N</td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Has the document been piloted? (not essential)</td>
<td>N</td>
<td></td>
<td></td>
<td>Not formally however, the processes outlined in the guideline have been taking place informally and the purpose of the guideline is to formalise the process between health, education and social care.</td>
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<tr>
<td>Criterion</td>
<td>Y</td>
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<tr>
<td>Is the process of development and changes made transparent through notes</td>
<td>Y</td>
<td></td>
<td></td>
<td>Minutes and drafts held by Children’s Therapy Head of Service (saved on the T drive). Additional information held by Speech and Language Therapist Liz Franklin.</td>
</tr>
<tr>
<td>of meetings and draft versions?</td>
<td></td>
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</table>
| Has an Equality Impact Assessment been undertaken on this guideline      | Y |   |   | Pages 13-23: Appendix I: Equality Impact Assessment  
EIA: Relevance Screening completed and logged with Richard Warlock and the C-Gap team (Stage 1 recommended).  
| Is there a clear action plan arising out of the EIA? If relevant         | Y |   |   | Page 4: Equality Impact assessment  
Pages 13-23: Appendix I: Equality Impact Assessment  
The Stage 1 EIA (Appendix I) highlighted the key equality groups for which this guideline could impact upon: disability, age, race, religious belief and dependants/caring responsibilities. As a result of the EIA upon guideline ratification and subsequent reviews a guideline dissemination process will be implemented. This will include the cascade of information to relevant staff groups and the development and distribution of newsletters/flyers for parents/carers. The assessment also reiterated the importance of:  
- Consulting with the child/young person and parents/carers in the development of the multidisciplinary feeding plan and goal setting.  
- Utilisation of an interpreter and translation services for those who have English as a second language.  
- Being culturally sensitive when offering advice and scheduling assessments and mealtimes.  
| Was there sufficient involvement/consultation in developing the EIA      | Y |   |   | Pages 13-23: Appendix I: Equality Impact Assessment  
Assessment Complied by: Katherine Slagle  
Lead Officer: Liz Franklin  
Others Involved: David Cundall, Barbara Shaw, John Chadwick, Jill Crampton, Verena Beard, Jen McAnuff and Helen Edmunds.  
The EIA was regularly discussed.                                          |
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<th>Criterion</th>
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<tr>
<td>Clarity</td>
<td></td>
<td></td>
<td>(replace instruction in red italics with your own information and complete blank boxes)</td>
</tr>
<tr>
<td>Is the guideline clear and unambiguous?</td>
<td>Y</td>
<td></td>
<td>This guideline was purposely sent for consultation to health, education, social care and voluntary/private sector colleagues to ensure accuracy of information and understanding. The roles and responsibilities were created by each agency/professional group and to ensure clarity. There are clear inclusion and exclusion criteria. There are clear dysphagia definitions. An abbreviation section was added for multi-agency use.</td>
</tr>
<tr>
<td>Is the guideline clearly referenced, demonstrating a link to the evidence base and/or best practice?</td>
<td>Y</td>
<td></td>
<td>Page 12: References Pages 24-25: Appendix II: Paediatric Speech and Language Therapy Dysphagia Risk Matrix</td>
</tr>
<tr>
<td>Has the guideline been developed after all other reasonable options of appropriate clinical intervention have been considered?</td>
<td>Y</td>
<td></td>
<td>Following an incident in 2007, NHS Leeds identified dysphagia as a high risk area. The Leeds Disabled Children’s Programme Board has subsequently given its approval to develop an inter-agency guideline. All agencies recognise the importance of a shared approach to ensure best practice which is coordinated, evidence-based and safe. The purpose of this guideline is to establish a consistent, cohesive approach between health, education, social care and the private/voluntary sector to manage the risks associated with moderate, major and/or profound dysphagia. The processes outlined in the guideline have been taking place informally however a formalised process was needed for these children/young people.</td>
</tr>
<tr>
<td>Has consideration been given to the information patients and/or carers should be given? Patient and Public Involvement Team involved?</td>
<td>Y</td>
<td></td>
<td>Katherine Slagle and Liz Franklin met with Siobhan Lendzionowski (PPI team). A two phase PPI action plan was created (referenced in 29.4.2010 and 10.6.2010 meeting minutes). Questionnaire developed and distributed to parents/carers (Reference Dysphagia PPI Strategy). As a result of the EIA upon</td>
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<td>Criterion</td>
<td>Y</td>
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<td>guideline ratification and subsequent reviews a guideline dissemination process will be implemented. This will include the cascade of information to relevant staff groups and the development and distribution of newsletters/flyers for parents/carers.</td>
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### Outcomes

**Are the health benefits to be gained from the guideline clear?**

Page 6: Objectives:
- Outline the roles and responsibilities of health, education, social care and the private/voluntary sector to clarify which staff groups and/or workers are to be involved in the assessment and management of children/young people with moderate, major and/or profound dysphagia (refer to section 8.1 for dysphagia definitions).
- Develop a process for the development and implementation of multidisciplinary feeding plans to manage the risks and improve outcomes for children/young people with moderate, major and/or profound dysphagia.
- Implement a multi-agency training programme to promote best practice.

Page 4: Purpose
The purpose of this guideline is to establish a consistent, cohesive approach between health, education, social care and the private/voluntary sector to manage the risks associated with moderate, major and/or profound dysphagia. When swallowing is a problem, the child/young person may not be able to receive adequate nutrition by oral feeding and/or they may be at risk of aspiration (food and/or fluids entering the airways). If aspiration occurs, the child/young person may appear visibly unwell however; this may not be immediately obvious (“silent aspiration”).

**Are the potential risks or harm from a recommendation described clearly?**

Pages 24-25: Appendix II: Paediatric Speech and Language Therapy Dysphagia Risk Matrix
Page 10: Risk Assessments
Pages 8-9: 8.4.1 Implementation Prior to the Child’s/Young Person’s Arrival at the Setting
Pages 9-10: 8.4.2 Implementation &
<table>
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<tr>
<th>Criterion</th>
<th>Y/N</th>
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<tbody>
<tr>
<td>Are outcomes clearly stated and measurable in order to enable monitoring through audit?</td>
<td>Y</td>
<td>Page 37: Appendix XI: Guideline Audit Proposal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Objectives:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- To ensure that children/young people with moderate, major and/or profound dysphasia receive:</td>
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<td>- A MDT assessment when their feeding difficulty is recognised and/or alters.</td>
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<td>- A timely, MDT review of their growth and feeding routine.</td>
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<td>- An agreed MDT feeding plan for which there is multi-agency responsibility.</td>
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<td>Estimated number in the audit sample: 25 children (10% of total 250 children) with moderate, major and/or profound dysphasia.</td>
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<td>Pages 13-23: Appendix I: Equality Impact Assessment (Prior to this guideline being developed an audit was conducted against the proposed guideline standards. A re-audit against these standards will be conducted by health (joint responsibility of the senior Speech and Language Therapist with responsibility for dysphagia and the paediatrician who leads on disability) with input from education, social care and ideally the private/voluntary sector. The guideline will be reviewed every three years. Each time the guideline is reviewed a current literature search will be conducted, dysphagia specific incidents and complaints (from each agency) will be reviewed and service user feedback will be assessed.)</td>
</tr>
<tr>
<td>Is the audit tool attached?</td>
<td>Y</td>
<td>Page 37: Appendix XI: Guideline Audit Proposal</td>
</tr>
<tr>
<td>Does/has a Legal position need to be sought?</td>
<td>N</td>
<td></td>
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<tr>
<td><strong>Dissemination and Implementation</strong></td>
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<tr>
<td>Are recommendations given as to how successful dissemination and implementation of the document will be achieved?</td>
<td>Y</td>
<td>Page 5: 3. Equality Impact Assessment (EIA)</td>
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<tr>
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<td>Pages 7-8: 8.2 Staff Requirements/Training Needs</td>
</tr>
<tr>
<td>Do implementation plans include consideration of anticipated resource implications (i.e. cost, time, training, equipment, prescribing etc)?</td>
<td>Y</td>
<td>Page 5: 3. Equality Impact Assessment (EIA)</td>
</tr>
<tr>
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<td></td>
<td>Pages 7-8: 8.2 Staff Requirements/Training Needs</td>
</tr>
<tr>
<td>Criterion</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Has the EIA been published</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Review</td>
<td>Y</td>
<td>N</td>
</tr>
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</table>

Author to date on completion: Katherine Slagle, 13.9.2010
Clinical Guideline Consultation Process

<table>
<thead>
<tr>
<th>Title of Document</th>
<th>Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Complex Feeding) in Community and Education Settings within Leeds</th>
</tr>
</thead>
</table>
| Author (s)                                                                       | David Cundall, Community Paediatrician  
Liz Franklin, Speech and Language Therapist |
| New/ Revised Document                                                            | New                                                                                                                                 |
| If the document is revised what revisions were required and for what reasons e.g. change in medical procedures or change in legislation | N/A                                                                                                                                 |
| Lists of persons involved in developing the guideline                             | David Cundall, Community Paediatrician, NHSLCH  
Liz Franklin, Speech and Language Therapist, NHSLCH  
Katherine Slagle, Children’s Therapy Head of Service, NHSLCH  
Barbara Shaw, Interim Head of Disability Services, Leeds City Council  
Andrea Robinson, Head of Service, Special Educational Needs, Statutory Assessment and Provision, Education Leeds  
John Chadwick, ISEN Development Officer, Education Leeds  
Jill Crampton, Children's Community Nurse, NHSLCH  
Verena Beard, Dietician, NHSLCH  
Jen McAnuff, Clinical Specialist/Deputy Manager Occupational Therapy, NHSLCH  
Kathy Goodwin, School Nurse co-ordinator S.I.L.C.S, NHSLCH  
Helen Edmunds, Clinical Psychologist, NHSLCH  
Karen Griffin, Paediatric Registrar, NHSLCH  
Kalyani Mulay, Community Paediatrician, NHSLCH |
<table>
<thead>
<tr>
<th>List of persons involved in the consultation process</th>
</tr>
</thead>
<tbody>
<tr>
<td>David Cundall</td>
</tr>
<tr>
<td>Katherine Slagle</td>
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<td>Karen Griffin</td>
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<tr>
<td>Kalyani Mulay</td>
</tr>
<tr>
<td>Karan Delaney</td>
</tr>
<tr>
<td>Sue Wilkinson</td>
</tr>
<tr>
<td>C-Gap Distribution</td>
</tr>
<tr>
<td>NHSLCH Speech and Language Therapy Team</td>
</tr>
<tr>
<td>NHSLCH Medical Team</td>
</tr>
<tr>
<td>NHSLCH Occupational Therapy Team</td>
</tr>
<tr>
<td>MHSLCH Dietetics Team</td>
</tr>
<tr>
<td>The guideline was sent to health, education, social care and voluntary/private sector colleagues to disseminate for consultation.</td>
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</table>
### Equality Impact Assessment – Relevance Screening Appendix 1

<table>
<thead>
<tr>
<th>1. Name of the policy/strategy/project or service</th>
<th>Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Complex Feeding) in Community and Education Settings within Leeds</th>
</tr>
</thead>
</table>
| Inter-Agency Guideline for the Assessment and Management of Children with Dysphagia (Complex Feeding) in Community and Education Settings within Leeds | 1. Outline the roles and responsibilities of health, education, social care and the private/voluntary sector to clarify which staff groups and/or workers are to be involved in the assessment and management of children/young people with moderate, major and/or profound dysphagia (refer to section 8.1 for dysphagia definitions).  
2. Develop a process for the development and implementation of multidisciplinary feeding plans to manage the risks and improve outcomes for children/young people with moderate, major and/or profound dysphagia.  
3. Implement a multi-agency training programme to promote best practice. |

<table>
<thead>
<tr>
<th>2. What are the main aims and objectives of the policy/strategy/project or service?</th>
<th></th>
</tr>
</thead>
</table>
| 1. Outline the roles and responsibilities of health, education, social care and the private/voluntary sector to clarify which staff groups and/or workers are to be involved in the assessment and management of children/young people with moderate, major and/or profound dysphagia (refer to section 8.1 for dysphagia definitions).  
2. Develop a process for the development and implementation of multidisciplinary feeding plans to manage the risks and improve outcomes for children/young people with moderate, major and/or profound dysphagia.  
3. Implement a multi-agency training programme to promote best practice. |  |

<table>
<thead>
<tr>
<th>3. Is this a key strategic document or a major project/programme</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>X</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>4. What impact will this policy/strategy/project or service have on the public or staff?</th>
<th>High</th>
<th>Medium</th>
<th>Low</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td></td>
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</table>

Please explain:
This will make feeding children with Dysphagia safer as MDT feeding plans:
  a. Are usually developed by speech and language therapists but are rarely used in a multidisciplinary (MDT)/multi-agency context.
  b. Are rarely signed off by managers, for example in schools or short break care settings, so that those feeding children in these places are unsupported.

Children and their families will have MDT feeding plans which could reduce the incidence of aspiration/inadequate nutrition.

Additional training for staff (health, education and social care) will be required.

<table>
<thead>
<tr>
<th>5. Is there any evidence, or other reason to believe, that different groups have different needs, experiences, issues and priorities in respect of this particular policy/strategy project or service etc?</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td></td>
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</tbody>
</table>

Please explain:
This guideline is being developed as in Leeds there are approximately 250 children with significant dysphagia, 98% of these children are disabled in other ways. MDT feeding plans are needed to protect these children.


If you have answered Yes to question 3, you should move straight on to a Stage Two Assessment.
If, for question 4 you have answered **Low**, there is no need to continue to an Equality Impact Assessment.

If for question 4 you have answered **Medium** and **No** for question 5, there is no need to continue to an Equality Impact Assessment.

If, for question 4 you have answered **Medium** or **Don’t Know**, and have answered **Yes** or **Don’t Know** for question 5 you should move on to a **Stage One** Equality Impact Assessment.

If, for question 4 you have answered **High**, you should consider whether you need to undertake a **Stage One** Impact Assessment or move straight to a **Stage Two** Impact Assessment.

<table>
<thead>
<tr>
<th>6. Based this screening please indicate if this policy/strategy/project or service should proceed to a Stage One or Stage Two assessment?</th>
<th>Stage One</th>
<th>Stage Two</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
<td></td>
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</tr>
</tbody>
</table>

Signed: [Signature]

Signed (Lead Officer): Liz Franklin

Sent to Richard Warlock and C-Gap: 22.6.2010 ks