



Royal College of Speech and Language Therapists

Who Cares? The Future of Adult Care and Support in Northern Ireland
15.03.13

Please find attached the Royal College of Speech and Language Therapists (RCSLT) submission to the above consultation.

Yours sincerely

Alison McCullough MBE
RCSLT Country Officer
Arthur House
41 Arthur Street
BT1 4GB

Heather Crawford MBE
RCSLT Country Councillor

Patron: Her Royal Highness The Countess of Wessex

Registered Office: 2 White Hart Yard, London SE1 1NX.

Tel: 020-7378-1200 Fax: 020-7403-7254 E-mail: postmaster@rcslt.org

A company limited by guarantee • Incorporated in England No. 518344 • VAT No. 795 8119 77 • Registered Charity No. 273724



Who Cares?

The Future of Adult Care and Support in Northern Ireland

Consultation Questionnaire

Please use this questionnaire to give us your views on the future of adult care and support services in NI. Please send your responses to:

Reform of Adult Care and Support Team
Department of Health, Social Services and Public Safety
Room D3.7
Castle Buildings
Stormont Estate
BELFAST BT4 3SQ

Email: reform.careandsupport@dhsspsni.gov.uk
Tel: 02890 765630
Fax: 02890 765621
Textphone: 02890 163426

Please send us your views by 15 March 2013.

NB. Before responding to this consultation please take note of the Freedom of Information requirements in Appendix 1 at the end of this questionnaire.

Consultee Details

Name (print):	Alison McCullough MBE
Organisation (if applicable):	Royal College of Speech and Language Therapists
Job Title (if applicable):	Country Policy Officer Northern Ireland Office
Address:	Arthur House 41 Arthur Street Belfast BT1 4GB
Email Address:	Janet.mcgookin@rcslt.org
Contact Telephone Number:	02890 446386
Date:	14 March 2013
Are you responding (please tick):	<input checked="" type="checkbox"/> On behalf of yourself? My organisation
Are you/they (please tick):	<p>a) over 65; <input type="checkbox"/></p> <p>b) under 65; <input type="checkbox"/></p> <p>c) disabled; <input type="checkbox"/></p> <p>d) a carer; <input type="checkbox"/></p> <p>e) a parent; <input type="checkbox"/></p> <p>f) other? <input type="checkbox"/> Professional Body</p>

Question 1:

Were you aware previously what care and support services are available to you, and where to go or who to ask to gain access to these services?

Please delete: Yes

Comments:

Question 2:

Do you agree with our vision for care and support?

Please delete: Yes

Comments:

The RCSLT consider that the core principles are founding principles and as such should not be considered as new. We agree with the vision but consider that it may be difficult to deliver in the context of the current financial position. The vision sets out to assure us that there will be improvements in ensuring that people will have their needs and unique abilities recognised and that there will be equity of provision. This will be particularly important for those with communication difficulties as they may lack the 'voice' to be heard. It will therefore be crucial that all staff have training from Speech and Language Therapists (SLTs) to ensure that they understand how to engage with people with a communication need.

It will also be crucial that at the start of any process of care planning that a full communication risk assessment should be carried to determine the communication needs of the individual prior to determining their needs and wishes for care provision.

Question 3:

Do you agree that care and support should continue to be provided on a partnership basis between the statutory, private and voluntary sectors?

Please delete: Yes

Comments:

The RCSLT agree that there are many benefits from cross partnership delivery. However there is a need to ensure that many of the negative aspects of this are mitigated against. In particular we have concerns about the lack of core standards in training across the private and voluntary sectors in the area of eating drinking and swallowing training and communication support.

There is a danger that services will be organised around time frames that suit the business model rather than the individual. For example, we have concerns that inappropriate meal times or rushed mealtimes may become more prevalent in the need to fit people into care slots rather than care slots around people. The rush to complete meal times may place the individual at risk of choking.

There is a need to ensure that individuals with swallowing difficulties also have a consistency of care providers so that subtle changes in swallowing deterioration will not be missed.

SLTs have an important role to play in training staff in dysphagia management. Huang (2006)¹ reports a positive effect from a swallowing training programme in preventing aspiration pneumonia. This study investigated the frequency of aspiration pneumonia in conscious stroke patients fed by a family member and examined the effect of introducing training in swallowing techniques by nurses. Patients were fed orally by a family member given general nursing information or fed orally by an experienced nurse trained in specific swallowing techniques. The incidence of aspiration pneumonia was 33.3% in group A and 6.3% in group B (P < 0.05). Training in swallowing during oral feeding offers clear protection against pneumonia in conscious stroke patients.

It is crucial therefore that care workers and carers have the necessary training in supporting people with eating drinking and swallowing difficulties so that risks are minimised and a consistency of care is delivered.

¹ Huang JY, Zhang DY, Yao Y, Xia QX, Fan QQ. (2006) Training in swallowing prevents aspiration pneumonia in stroke patients with dysphagia. *J Int Med Res.* 2006 May-Jun; 34(3):303-6.

It will also be important that communication support needs are fully understood by all those delivering care to an individual. *Communication passports* developed by speech and language therapists are a tool that enable people with communication support needs to inform others of their preferred communication methods and their likes and dislikes.

We are concerned that the unique role of an SLT in assessing communication support needs and recommending communication strategies will be overlooked. SLTs are uniquely trained to assess and diagnose communication disorders and recommend communication support strategies.

Question 4:

Do you agree care and support should focus more on earlier intervention and prevention of loss of independence? Should savings made in hospitals be reinvested in preventative care and support services?

Please delete: Yes

Comments:

The RCSLT believe that Speech and Language Therapists (SLTs) have the skills to support this transition in focus. SLTs are able to contribute significantly in delivering early intervention, preventative and palliative care.

As stated previously, they have a unique role in the management of dysphagia which reduces the risk of associated complications that may require hospital admission such as chest infection, aspiration pneumonia, dehydration and malnutrition. These patients may present with a range of long term conditions such as Respiratory Disease, Progressive Neurological Diseases (Parkinson's Disease, Multiple Sclerosis, Dementia) and elderly frail people with general medical conditions such as UTI which affect swallowing.

Dysphagia carries a sevenfold increased risk of aspiration pneumonia and is an independent predictor of mortality. Early recognition of dysphagia and intervention in hospitalized patients is reported to reduce morbidity and use of hospital resources (Altman et al., 2010)².

² Altman, K.W., Yu, G.P., & Schaefer, S.D. (2010). Consequence of dysphagia in the hospitalized patient: Impact on prognosis and hospital resources. *Archives of Otolaryngology-Head & Neck Surgery*, 136(8), 784-789.

Aspiration occurs in about 40% to 50% of stroke patients with dysphagia (Marik & Kaplan, 2003)³. The older adult with one of these conditions is at even greater risk for aspiration because the dysphagia is superimposed on the slowed swallowing rate associated with normal aging.

For people aged over 75 the reported incidence of community acquired pneumonia is 3–5 fold higher than in the general population. Furthermore, frail older people living in (residential) care homes have more functional disabilities and diseases and have, consequently, a higher risk of developing aspiration pneumonia than community-dwelling older people.

Chest infections are a major cause of hospital admission in the elderly and many people with COPD have swallowing difficulties as an underlying condition which often goes unidentified. Symptoms of COPD include shortness of breath, increased fatigue, a chronic cough, loss of appetite and weight loss which mirror the symptoms of dysphagia thus making a differential diagnosis difficult. COPD was shown to be the most significant risk factor for aspiration pneumonia in nursing home patients (Langmore, 2002)⁴. It is therefore imperative that the SLT is integral to the management of the patient with respiratory compromise (Alexander 2009)⁵. The Speech and Language Therapist is therefore key in establishing a differential diagnosis and should be included as a core team member.

The RCSLT is concerned that SLTs are currently not considered as core members of Community Urgent Care Teams, Community Respiratory Teams and Rapid Response teams.

SLTs can identify and support people with dysphagia, their families and carers and can work with other members of the MD team to optimise nutrition and hydration for patients presenting with dysphagia and thereby reduce hospital admissions. Concerns have also been raised that in hospital there is a 48 hour standard for swallowing assessments; in community services urgent referrals are currently seen in two weeks. With transition of acute care to community this inequity needs to be urgently addressed.

³ [Marik and Kaplan, 2003](#) P.E. Marik, D. Kaplan Aspiration pneumonia and dysphagia in the elderly Chest, 124 (2003), pp. 328–336

⁴ LANGMORE, S.E., SKARUPSKI, K.A., PARK, P.S. and FRIES, B.E., 2002. Predictors of aspiration pneumonia in nursing home residents. *Dysphagia (0179051X)*, 17(4), pp. 298-307.

⁵ ALEXANDER, J.E., 2009. Assessment and Treatment Approaches for the Patient with COPD. *Perspectives on Gerontology*, 14(2), pp. 33-36.

Below is an example of how SLTs can reduce costs by preventing hospital admissions and also by facilitating early hospital discharge.

Case Study

Sandwell Community Healthcare Services improved dysphagia management and piloted a community dysphagia rapid response assessment service. Quality was improved by allowing more patients to be managed at home for terminal illnesses, and increasing empowerment for patients, their carers and staff. Productivity has been improved by reducing hospital referrals and admissions.

Evidence suggests that 45% of patients with palliative care needs report communication or swallowing (dysphagia) problems (Communicating Quality 3, Royal College of Speech & Language Therapists 2007). Therefore, based on current palliative care figures within Sandwell, 1,388 patients each year will expect to have problems with swallowing and communication at the end of their life and would benefit from Speech and Language Therapy (SLT).

This project aimed to reduce acute hospital attendance, length of stay and repeat admissions by:

1. Community rapid response dysphagia assessments for patients at risk of aspiration; and
2. Training of primary care staff in the management of patients with dysphagia

The three components to this proposal were:

Responsiveness

A rapid response dysphagia service in the community, where urgent patients are assessed within 4 working hours, thereby reducing hospital admissions.

Prevention

Extensive training to community staff to enable frontline dysphagia management 24 hours, 7 days a week long term.

Strategy Develop and implement a palliative feeding Care Pathway to ensure patients with dysphagia related end of life conditions are managed by community services, ensuring patients die in their place of choice whilst they, their relatives and carers feel supported.

This service development supports the policy 'Care closer to home', 'Admission avoidance' and ensures that the patient has choice over their preferred place of death. It targets older people, neurological conditions & palliative care.

References

- National Service Framework for Long Term Conditions (2005)
- End of Life Care Strategy - promoting high quality care for all adults at the end of life (2008)
- Report from West Midland End of Life Clinical Pathway Group
- NHS Operating Framework 2009/10
- Our care our health our say, Darzi (2008)
- General Medical Council (GMC) (2002) Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making. London: GMC
- The British Psychological Society & The Royal College of Psychiatrists, (2007). A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care. Published by The British Psychological Society and Gaskell. ISBN: 978-1-85433-451-0

Question 5:

Do you agree that people who need care and support should have control over how their assessed care and support needs should be met?

Please delete: Yes

Comments:

The RCSLT agree that it is important to enable individuals to participate in decisions about their future care. However, individuals with communication disability will need appropriate help to engage in this decision making process. Supporting someone with communication disability requires an in depth knowledge of their receptive and expressive language ability and their alternative or and augmentative communication systems. If individuals are to be given more say and control over how their support needs should be met, it is vital that arrangements are put in place to support those who have difficulty communicating their needs and wishes.

The RCSLT is concerned that people with communication difficulties will be denied choice and control where others deem that it is clinically inappropriate or impracticable for them to make choices. If an untrained healthcare provider makes these decisions on the individual's behalf, variable outcomes may result dependent on the healthcare professional and the level of information that they possess. There is a fear that choice may be limited if it is deemed too time-consuming or complex to engage with someone with a speech, language or communication need.

There needs to be clarity on who would act in the interests of the patient if their choice is being limited or denied. Would the patient be able to nominate an advocate, family member or carer to exercise choice on their behalf? Social workers and SLTs could work together in this process to provide communication support if required.

The RCSLT is concerned that health professionals may deem someone to lack capacity to consent or to make decisions due to their communication disability when in fact with the correct support the individual could fully participate in decisions around their own healthcare provision. All healthcare professionals, nurses, doctors and GPs should receive initial mandatory and ongoing training to understand communication problems, from a trained speech and language therapist to ensure that they are able to understand and communicate with the individual.

Patients with speech, language and communication needs will require support to be able to exercise choice. Some patients may lack capacity to make decisions about their own care for example those with more advanced forms of dementia or following a stroke. However, it should be recognised that other people with communication needs in receipt of the correct communication support are perfectly capable of exercising choice and making decisions. Appropriate support from speech and language therapists will ensure equitable representation across all care groups, universal and specialist services.

For engagement to be truly meaningful individuals must be able to access information in easily understandable formats (e.g. easy read material, symbols, sign, Talking Mats) receive support and preparation for the participation process, as well as access to modes which enable them to express their views.

Question 6:

Do you agree that we have identified the right areas for reform?

Please delete: Yes

Comments:

Question 7:

Do you agree that there should be a balance between fulfilling individual preferences for how care and support needs are met and ensuring that resources are used efficiently to provide support to as many people as possible?

Please delete: Yes

Comments:

The RCSLT agree that fulfilling individual preferences for how care and support needs are met and ensuring that resources are used efficiently is a core principle. However, with the elderly and with people who have communication disability or complex needs, the process of scoping and choosing who to engage with for support will be even more stressful. Individuals such as these will require quality advice to ensure they are enabled to make the best decisions about their own care needs.

In order to achieve this goal, the DHSSPS will need to test out how this works in practice for people with communication difficulties and for those with dementia or mental health issues. Whilst fulfilling individual preference is enabling for individuals with full cognitive abilities, it is much more of a challenge for users with mental health and communication disabilities. The DHSSPS should plan to engage with professional bodies and voluntary organisations in developing accessible information and clear guidelines on how to work through this process. It should also put in place plans to provide more support for people who would find this challenging.

The RCSLT agree that services should be responsive to the needs of people when this is in their best interests. People with communication disability are often very isolated in their own homes and may be negatively impacted by such a policy. Policy should reflect individual choice and should take account that in some cases being cared for at home may not always be the optimum environment for someone with a communication difficulty. Ensuring that these individuals have daily contact with someone who can support their communication and encourage them to *chat* will be of huge importance.

Social isolation and mental health problems are exacerbated by lack of social communication opportunities. A residential setting with plenty of activities for residents to engage in is a much more stimulating environment for someone with a communication difficulty. Access to local communication/conversation groups would be an important provision in such cases.

Question 8:

Do you think that the current balance of responsibility between government, people who use services and carers is fair/right?

Please delete:

If not, how should we change the role of:

- (a) Government?**
- (b) People who use services?**
- (c) Community and Carers?**

Comments:

Community and Carers

The RCSLT consider that with a shift in focus to community provision, and personal choice, there may be undue pressure placed upon relatives to become carers for family members.

The person requiring the care may prefer to stay at home but his/her relatives also have rights to express their own preferences particularly when the pressure on family members as carers becomes too great and puts their own health at risk. Carers will also require significant training to ensure that they have the skills to support their family members.

We are also concerned that a balance needs to be ensured so that children do not become burdened by taking on additional care roles and that the rights of children are not impacted.

Government

In order to ensure that families can cope with additional burdens placed upon them, the government needs to factor in a process of review.

Government also needs to consider how it will balance the human rights of the person needing care at home with the rights of family members to have a family life which is not impacted by caring responsibilities.

HUMAN RIGHTS AND EQUALITY IMPLICATIONS

Section 75 of the Northern Ireland Act 1998 requires Departments in carrying out their functions relating to Northern Ireland to have due regard to the need to promote equality of opportunity:

- ❖ between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- ❖ between men and women generally;
- ❖ between person with a disability and persons without; and
- ❖ between persons with dependants and persons without.

In addition, without prejudice to the above obligation, Departments should also, in carrying out their functions relating to Northern Ireland, have due regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group. Departments also have a statutory duty to ensure that their decisions and actions are compatible with the European Convention on Human Rights and to act in accordance with these rights.

At this early stage in the reform process the Department has not carried out an Equality Impact Screening exercise, as the Discussion Document does not contain any policy decisions or changes. The Department, does, however, intend to carry out a Screening exercise at a later stage.

For this reason, if you feel that there are any particular issues in relation to equality and human rights which the Reform Team should take into consideration at this stage, please outline these below:

The RCSLT is concerned that breaches of human rights may occur if individuals with communication support needs are not fully engaged in decisions about their health care provision.

As stated previously the RCSLT believe that there must be built in safeguards and alternative options to enable people with communication difficulties to participate in making decisions about their care.

A communication risk assessment should be carried out as part of the initial care planning process to establish if additional communication support and assessments are required.

Speech and language therapists are the experts in communication and work with other professionals to ensure that they feel competent to allow patients to exercise their own choice and to know when further expert input is required to support the patient.

All healthcare professionals, nurses, doctors and GPs should receive training in communication disability awareness, from trained speech and language therapists to ensure that they are able to understand and communicate with patients who have communication support needs.

To make shared decision making a part of healthcare professionals 'working practice' case examples should be provided of when patients with communication disabilities choose not to have medical intervention e.g. a patient with motor neurone disease who chooses to refuse PEG feeding.

The RCSLT would like an assurance that an SLT who specialises in communication aids and alternative and augmentative communication supports will be included on any implementation groups to ensure that the most vulnerable (those who cannot express themselves verbally) are adequately represented. This is critical if the needs of people with communication difficulties are to be factored in to adult care and support provision.

Appendix 1

FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case.

This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation.

However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential. If you do not wish information about your identity to be made public please include an explanation in your response.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Secretary of State for Constitutional Affairs' Code of Practice on the Freedom of Information Act provides that:

- the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department's functions and it would not otherwise be provided;
- the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature; and
- acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner.

For further information about confidentiality of responses please contact the Information Commissioner's Office at:

Information Commissioner's Office Northern Ireland

51 Adelaide Street

Belfast

BT2 8FE

Tel: 028 9026 9380

Fax: 028 9026 9388

Email: ni@ico.gsi.gov.uk

Website: <http://www.informationcommissioner.gov.uk/>