

Report on

Communication Aids Project

European Year of People with Disabilities 2003

Introduction

The following is the report of a project carried out by speech and language therapists/ logopedists in the European Union and observer states (Norway, Cyprus, Estonia and Switzerland). This was carried out by the speech and language therapists/ logopedists representatives of CPLoL (Comite Permanent de Liaison des Orthophonistes-Logopedes de L'Union Europeene/ Permanent Liaison Committee of EU Speech and Language Therapists and Logopedists as a contribution to the activities to celebrate the European Year of People with Disabilities 2003.

As the adult sub group of the Prevention Commission of CPLoL we decided to look into the provision of communication aids to adults with acquired communication difficulties within the European Union.

Sophisticated communication aids have been developed. Some of these are suitable for some communication disabled people, e.g. following head injury, stroke, head and neck cancer, laryngeal cancer etc..

Access to these aids would make a huge difference to the quality of the lives of the people who could benefit from them. The access to a communication aid may determine whether the person is condemned to remain socially and economically isolated or not.

Having a communication aid may allow someone to return to work, be able to communicate with his or her relatives and friends, integrate back into society.

Background

"For a number of years, the European Union has been active in encouraging the social and economic integration of people with disabilities. In both 1996 and 1999, the Council adopted resolutions on equality of opportunity for people with disabilities. In the conclusions of the Lisbon European Council (March 2000) a call is made for Member States to take greater account of social exclusion in their employment, education and training, health and housing policies and define priority actions for specific target groups, such as people with disabilities. The European social agenda approved by the European Council meeting in Nice (December 2000) states that the European Union will develop, in particular during the European Year of People with Disabilities (2003), 'all action intended to bring about the fuller integration of disabled people in all areas of life'."

“The year 2003 marked the 10th anniversary of the adoption by the UN General Assembly of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which have enabled considerable progress to be made in an approach to disability in accordance with human rights principles.”

(Ref: Official Journal of the European Communities L335 19th December 2001)

Population concerned and argument

People who have had strokes, traumatic brain injury e.g. road traffic accidents etc., progressive neurological disorders (e.g. motor neurone disease, multiple sclerosis), and head and neck cancer possibly involving the larynx may have acquired communication disability. They may be unable to use speech, language or voice and may require a communication aid as appropriate.

It must be remembered that these people had been leading normal active lives and contributing to the economy of their country until the episode that led to the communication disability.

Communication is a key function in social and economic life. Communication enables human contact and relationships, it is crucial for making needs known and to express feelings. It is essential to be able to communicate in order for an individual to take responsibility for and to manage his/her own life and to be able to be autonomous. An individual needs to be able to communicate in order to be independent and actively participate in life. Communication is important to society and also to the self-esteem of the individual. Communication therefore is fundamental to the quality of life.

People with communication disability are in danger of being excluded from employment and being socially isolated. This isolation could lead to depression which is costly and difficult to treat and therefore may possibly lengthen the process of rehabilitation or render the individual may be unfit for rehabilitation.

The lack of access to communication aids and the training for their use may result in discrimination of the communication disabled and prevent their integration into society.

Having a communication disability is not often recognized in society and in general it is a **hidden handicap** whose importance/significance is not fully appreciated.

Having a communication aid may allow someone to return to work, be able to communicate with his/her relatives and friends and integrate back into society.

As a result of the discussions we have had in CPLOL (Comite Permanent de Liaison des orthophonistes/logopedes de L'Union Europeene/ Permanent Liaison Committee of Speech and Language Therapists/Logopedists in the European Union) we were aware that there were some differences in the availability and provision of and information about communication aids. We decided to fully investigate this within the member states of the European Union (and observer states: Norway, Cyprus, Estonia and Switzerland) to have a clearer picture of the situation so that we could draw conclusions and make recommendations.

Hypothesis: There is not equality of access to communication aids for adults with acquired communication difficulties throughout the European Community.

The result of the survey, we believe, will expose the inequality of access to these aids and the haphazard way they are currently funded; sometimes relying on charity with often little state provision in some cases.

Method

We decided to design a questionnaire to gather the necessary information.

The questionnaire was drawn up and sent to CPLOL members (and observers) asking them to collect the information from their colleagues in the Member States and observer countries.

The questionnaire has 4 sections, which reflect the first two objectives:

1. to identify the situation concerning access to the provision of communication aids for the communication disabled (adults) in Europe.
2. to make recommendations about the provision of communication aids (for adults)

The third objective is to disseminate the information gathered to all speech and language therapists/logopedists as an information (database) source of what equipment is available which would be of benefit to their communication disabled clients

The information was collated and analyzed by the subgroup.

Graphs were drawn up (see results).

The responses from all the members indicate that the information is representative of the situation in Europe.

In using the CPLOL members we had no control over the validity of the information given except that at the CPLOL meetings we reminded members of the details of the project and the information we wanted so that they made their responses using further information from their colleagues.

In the questionnaire we did not identify the ratio of SLTs working with these client groups to the population and how those prescribing or suggesting an aid had obtained the information. Although we didn't ask for this information we realize that it may have had an impact on the demand for communication aids.

Results

The results of the questions are put in four tables drawn up below.

1.a What kinds of communication aids are used/available in your country (for adults) for laryngectomy patients?

Country	Vibrator (Servox etc)	Bloom singer valves	Provox	Other
Sweden	X	X	X	
United King- dom	X	X	X	
Italy	X	X		
Ireland	X	X	X	
Finland	X		X	
Germany	X	X	X	
Greece	X	X	X	
Denmark	X		X	
Spain	X	X	X	
Estonia	X			Provox 2 Better stoma care
Switzerland	X	X	X	
Cyprus	X		X	
Norway	X		X	
Austria	X	X	X	
Netherlands	X	X	X	
Portugal	X	X	X	
Belgium	X	X	X	voice master et cyranose
France	X	X	X	Filtres trachéaux Provox avec ou sans implants phonatoires (+ mains libres) et Cyranose avec ou sans implant phonatoire
Luxembourg	X	X	X	

As this table shows the most used communication aids for laryngectomy patients are available in most of the countries.

1.b Communication aids for use with people post stroke, post head injury etc

Country	Light-writer	Liberator	PC based software	Telephone aids	Pictorial systems	Alphabet board	Other
Sweden	X		X	X	Pictogram PCS, Nilbild Ica Pictures Rebus	X	Macaw Tech-talk
United Kingdom	X	X	X	X	Boardmaker	X	
Italy							
Ireland	X	X	X	X	X	X	
Finland	X		X	X	PCS, PIC, Bliss	X	
Germany	X	X	X	X	X	X	X
Greece			X	X	Makaton program	X	
Denmark	X		X	X	Pictogram, Bliss, Pointing books	X	Alfa- talker
Spain	X	X	X	X	Bliss, SPC	X	
Estonia	Due to lack of funds no aids are distributed						
Switzerland	X	X	X	X	X	X	
Cyprus			X		X	X	
Norway	X		X	X	X	X	Eye- pointing
Austria	X		X		X	X	
Netherlands	X	X	X	X	X	X	
Portugal				X		X	
Belgium			X		Communication book	X	
France			X	X	X	X	
Luxembourg	X	X	X	X	X	X	

As this table shows a lot of different kinds of communication aids are available for people post stroke, post head injury etc. in most of the countries.

2. Who funds these communication aids?

Country	Social security system	Charity	Part charity part social security	The patient him/herself	Part patient part social	Patients health insurance	Other
Sweden	X	X					
United Kingdom		X		X		X (occasionally)	PCT
Italy	X		X	X	X	X	
Ireland	X	X	X	X			
Finland	X						
Germany	X					X	
Greece					X	X	
Denmark	X						
Spain	X			X	X		
Estonia					X		
Switzerland	X	X	X	X	X	X	
Cyprus		X		X			
Norway	X						
Austria	X (for le)	X					National funds for hc
Netherlands	X						
Portugal				X	X		
Belgium	X	X	X	X	X	X	AWIPH
France	X			X	X	X	les fonds d'aides aux personnes handicapées, et parfois des associations caritatives
Luxembourg	X						

As the table above shows, there are a lot of different ways to get a communication aid if you need one in order to have a social life or even get back to work. What seems unfair is that in many countries the communication disabled person is dependent on ether charity, enough money yourself or a good insurance to have one.

3. Who advises/assesses the person to decide that a communication aid is necessary?

Country	Doctor	Speech and language therapist	Occupational (ergo)therapist	Physiotherapist	Other
Sweden	X	X	X		
United Kingdom	X With a team	X	X With a team		
Italy	X				
Ireland		X			Assertive Technology personnel
Finland	X	X	X	X	
Germany	X	X			
Greece	X	X	X	X	
Denmark	X Laryngectomy	X			
Spain	X	X			
Estonia	X	X			
Switzerland	X	X	X		
Cyprus	X	X			
Norway	X	X	X	X	
Austria	X(le)	X			
Netherlands	X	X	X		
Portugal	X				
Belgium	X	advices			
France	X				prescription d'un médecin ORL, remboursé par la sécurité sociale sur tarif conventionné
Luxembourg	X	X	X	X	

As this table shows both doctors and speech therapists do the assessment for recommendation of communication aids, sometimes also an occupational therapist. We would suggest that a speech therapist who has the knowledge about communication always should be part of the assessment.

Discussion

It was evident from the early responses that we had not asked about the ease or difficulty of obtaining funding clearly enough. We had expected that this information might have been included in the comments section. This was amended on the questionnaires sent out later.

It seems that most of the communication aids can be obtained in the majority of the countries but in some the person needing them can more easily access them.

In many countries there was considerable difficulty in obtaining the necessary funding which delayed the provision of them (UK), in some countries they could only be provided if the disabled person could purchase them (Spain), however, in others there were examples of best practice, where once it had been proved that the person needed the aid it was funded by state funding (Netherlands, Sweden).

Conclusion

As we hypothesized there were considerable differences between the countries in the method of funding and the ease of obtaining funding.

The Council of the European Union has emphasized the importance of the standard of living and the quality of life of the people within them. In the project we have focused on the plight of people with communication disabilities and the poor quality of life they will have if they are denied access to appropriate communication aids.

The General Assembly of the United Nations states in the Universal Declaration of Human Rights, 217A (III) 1948-1998

"All human beings are born free and equal in dignity and rights"

"Everyone has the right to work..."

"Everyone has the right freely to participate in the cultural life of the community..."

Recommendations

We recommend that every adult who needs (and can benefit from) communication aid should have access to the one appropriate for their needs. This should be free and should be available as soon as the person needs it without a long period of waiting and should be funded by the appropriate social security system in the member states.

It is however not appropriate for all communication disordered adults to be supplied with a communication aid. They should only be supplied when appropriate assessment by a speech and language therapist/logopedist/orthophoniste indicates the need and teaches the use.

In order to provide this there needs to be information about communication aids for adults, centralized stocks and the possibility of being trained to use them in all countries.

Appropriate assessment should be carried out by suitably qualified Speech and Language Therapists/Logopedists.

Protocols should be written to ensure that Speech and Language Therapists take the pivotal role in the provision of communication aids.

We would therefore ask that consideration is given to eradicating the anomaly of the provision of these essential aids and that member states ensure a mechanism within their appropriate statutory bodies to facilitate access by instituting some simple speedy process for application to funds, which will be made available for communication, aids.

In line with the third part of our aim in carrying out this project, to increase and make available information concerning communication aids for adults. We would suggest that private health insurance companies should be aware and also take some responsibility in providing information about communication aids.

Because of the increasing use and availability of the Internet and as a result of this project we think that there should be a website to make easily available all the information about communication aids (for adults) and that this should be updated regularly. We would like to propose this as an on going project to be initiated by CPLOL using private funding from companies and insurance companies with some European Union backing via CPLOL.

Adult sub group
Prevention Commission
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