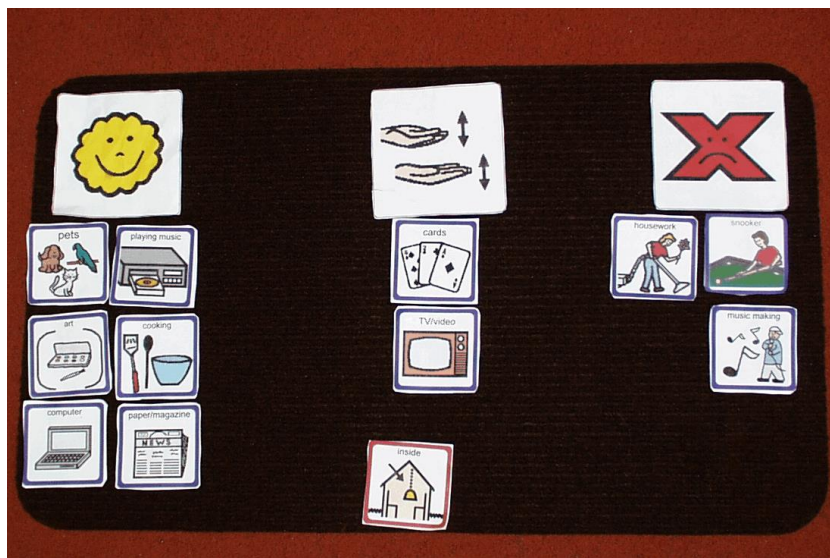


Making Choices at the Time of Transition for Young People with a Learning Disability



Lois Cameron and Joan Murphy

**AAC Research Unit
Department of Psychology
University of Stirling**

**Final Report to
Viscount Nuffield Auxiliary Fund**

November 2000

BACKGROUND:

The time when a young person leaves school is a significant period of transition. For people with a learning disability the choices can often be limited and it can be difficult to ensure their voice is heard. There is recognition that periods of transition merit particular support and attention. The Beattie report: 'Implementing Inclusiveness' (1999) states that '*young people with learning disability are at risk of social exclusion and difficult transition on leaving school and during subsequent transitions*'. The addition of communication impairment is likely to compound the problem. The Scottish Executive review of services: 'Same as You' (2000) states that 80% of people with a learning disability have some communication difficulty and that 50% have a significant communication impairment. A review of services to young adults by Optimum Health Services NHS Trust (1999) found that:

- *Young people often do not feel involved and informed in making choices.*
- *Young people with severe learning disability need planning for what happens when they leave college.*
- *Young people with communication difficulties had no independent voice in transition planning.*

It is acknowledged that involvement in life planning is central to good service delivery. Current legislation (Children in Scotland Act 1995) states that it is obligatory to include the views of children and young people in reviews, further needs assessments and decisions affecting them. Given the difficulties entailed, at present the involvement of young people is no more than a 'lip service', particularly if the individual has communication impairment in addition to their learning disability (Lloyd et al 1996).

This project focused on the need to develop a tool that will allow young people with a learning disability to consider and be actively included in discussion and decisions about the choices available to them at these crucial times of transition. As part of a previous research project, **Talking Mats** (Murphy 1998) was developed which enabled people with cerebral palsy and communication difficulties to express their thoughts and views and this project wished to consider the suitability and usefulness of this framework with young people with learning disabilities.

AIMS:

The project had 3 specific aims:

1. Develop a tool that would allow young people with learning disability and communication impairment to communicate their views on the choices, hopes and fears at the time of transition from school to college or day centre.
2. Identify the range of issues which are important to young people with a learning disability at this time of transition
3. Identify the prerequisites in term of individuals' skills in order for them to access **Talking Mats**

Making choices at the time of transition for young people with a learning disability







METHOD:

Talking Mats is a pictorial framework based on 3 sets of picture symbols that are presented to the person with the communication difficulty.

1. **issues** which are relevant to transition
2. **factors** relating to each issue
3. **emotions** to allow participants to indicate their feeling about each factor.

The main issues and factors relating to transition were selected following a search of the relevant literature in conjunction with discussions with speech and language therapists who work in the field of learning disability. In addition workshops were carried out with staff in a Further Education College and a Day Centre to refine the issues and factors.

The **issues** identified were:

Accommodation	
Day activity-work/education	
Leisure- indoor interests	
Leisure -outdoor interests	
People	
Transport	

A wide range of **factors** was prepared to include as many possible choices which might be available to young people at this time of transition. For example within the issue of **transport**, the following factors were presented: family car, taxi, regular bus, dial-a-journey bus, train, walking/ wheelchair, bike, travelling on own,.

A range of 3 emotions was presented along the top of each mat :



happy
(things you like)



unsure
(things you're not sure about)



unhappy
(things you don't like/want)

Each '**mat**' had the range of emotion symbols along the top and focused on 1 issue. For each issue, the relevant picture symbols were presented to the participants who then selected the ones that were important to them and placed them under the appropriate emotion thus building up a composite picture of there

Making choices at the time of transition for young people with a learning disability

views. Blanks were always presented so that the participant could add factors which the researchers had omitted. The framework was piloted and subsequently modified by adding a training issue (**food** likes and dislikes) to ascertain that the participants understood the procedure. In addition the framework was adapted throughout the project in consultation with the participants.

The symbols used were Picture Communication Symbols (PCS) which were produced on the software package Boardmaker™¹.

PROTOCOL:

Ethical permission was obtained from the Ethics of Research Committee of Forth Valley Health Board and the Speech and Language Therapy Department identified 17 possible participants. The GPs and Speech and Language Therapists involved with each participant were informed in order to check if there were any reasons why any participant should not be included. Great care was taken to ensure that participants understood what was being asked of them and they were given both verbal and pictorial information. A witness who knew the participant well was asked to countersign the consent sheet stating that they had observed how consent was obtained, that the participant had understood their involvement and was not being placed under pressure to do so. Three of the young people approached chose not to be involved which was considered an indicator that the project had been explained well and that those who did **not** wish to participate were able to say so. Two of the 17 were unwell and therefore not included. Twelve young people were therefore involved in the study. Each participant was visited 3 times. First to explain their involvement, second to carry out the interview and finally to provide feedback and give them a copy of their completed 'mats'. A video recording was made of each interview, a digital photograph was taken of each completed 'mat' and detailed field notes were taken. The video recordings were analysed by 3 researchers to establish inter judge reliability. A coding framework was used which included a rating scale from 1 to 5 for each participant's understanding of the issue, participant's confidence at manipulating the picture symbols (either manually or visually), participant's confirmation of the researchers interpretation and participant's satisfaction with each completed 'mat'. The 'mats' were analysed using cognitive mapping (Jones 1985) to identify the range of factors which are important to young people with a learning disability at the time of transition and to identify the prerequisites needed to allow people to use the mats successfully. At the follow up visits the participants were asked to comment if they still agreed with the views expressed on each 'mat' and any changes were noted.

¹ The Picture Communication Symbols (PCS) are ©1981-1999 Mayer Johnson Co. and are used with permission - Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA

Making choices at the time of transition for young people with a learning disability

PARTICIPANTS:

All were known to the Speech and Language Therapy Learning Disability Service of Forth Valley Primary Care Trust and had a range of both learning and communication difficulties as the following tables show:

Aetiology:

Number	Aetiology
5	Cerebral Palsy
2	Downs Syndrome
1	Autism
1	Foetal alcohol syndrome
1	Hydrocephalus
2	No known Aetiology

In addition, five of the participants were regarded as having behaviour that significantly challenged services.

Communication Skills:

Information regarding the participants' functional communication ability was obtained from the speech and language therapy department.

Number	Functional comprehension
2	Contextual and key word comprehension
5	Two to three information carrying (KEY) words
2	Specific processing and sequencing difficulties
3	Mild difficulties
Expressive communication method	
6	Speech
5	Low tech communication aids
2	High tech communication aids
4	Signing

The participants' expressive methods varied from those who used primarily speech to those who used augmentative systems such as high tech communication aids, low tech communication books and Makaton signing. Several participants combined a variety of methods.

Transition events:

All participants were facing or had recently faced at least one area of transition in their lives, which is illustrated in the following table:

Number	Transition factor
4	Change of accommodation
4	School to college
3	School to day centre
1	College to day centre
1	College to work

Making choices at the time of transition for young people with a learning disability

1	Day centre to undetermined. This participant's choices were further limited due to having been excluded from day centre and college.
---	--

RESULTS:

All participants were able to use the *Talking Mats* to some extent as a framework for expressing views on the choices they wished in their lives. Ten participants were able to complete mats on all six issues identified as being important at transition. There was inter-judge reliability on all issues for eight participants but disagreement between the judges on two mats. The two participants who completed those mats both had severe communication difficulties. One participant's method of confirmation was confusing as his vocalisation contradicted his facial expression. For the other participant the judges disagreed as to the degree to which he understood the concept of living on his own. The two participants with the most severe learning disabilities were unable to complete all six mats and were presented with the most concrete issues, **indoor** and **outdoor leisure activities**

The mid point (indicating uncertainty) was only used by the five participants whose comprehension difficulty related to sequencing and processing of connected speech. For two of the participants, the mid point appeared to be a distraction and for them the mat was reduced to a two point scale.

Leisure:

All participants identified a wide range of leisure interests, none of which were unrealistic or excessively costly. For one client who had a severe learning disability, little functional speech and had just moved from school to day centre, two clear **likes** emerged that the staff knew nothing about - one was horse riding and the other trains.

For two people, boredom was considered to be a factor that contributed to their challenging behaviour. Their mats beg the question as to why they were bored. Looking at the range of activities they had placed at the positive end of their 'mats', it seems more likely that they were frustrated at their inactivity.

The Appendix contains a selection of individual 'mats'.

The following tables illustrate some of the significant views of the 10 participants who completed all 6 issues. The results were confirmed not only by the completed 'mats' but also from observing the participants' facial expressions and final confirmations on the video. As not all the participants chose every factor in some cases the results do not add up to 10.

Accommodation	Positive	Unsure	Negative
With family	9	0	1
Group Home	6	0	4
Own tenancy	3	2	4

Making choices at the time of transition for young people with a learning disability

The participants expressed positive views about staying in the family home apart from one who clearly did not wish to live there. Two were unsure about living on their own and 4 definitely did not want to live on their own.

Day Activity	Positive	Unsure	Negative
Day Centre	3	3	3
College	9	1	0
Work	4	2	3
Home all day	1	2	7

Nine of the 10 participants wanted to go to college and the other was unsure. Three who were not attending college wished to and one who was due to finish college indicated he wished to stay on. Clearly all wanted their day to be structured with meaningful activity and for 9 participants staying at home all day was an option about which they were either unsure or unhappy.

People to spend time with	Positive	Unsure	Negative
Family	9	0	1
Carers	8	0	0
New Friends	7	0	2
Old friends	6	1	2
Boy/Girl friend	6	2	0
Family friends	5	0	1
Time on own	1	1	3

Again the importance of family is demonstrated (1 specified that he did not like his brother) and 8 were happy with their carers. One expressed a clear dislike at spending time with her parents' friends and 6 expressed a wish to stay in touch with old school friends. Spending time on one's own was something not many had considered. This was confirmed by watching the participants' facial expressions on the videos.

Transport	Positive	Unsure	Negative
Car	9	0	0
Dial a Journey	7	0	0
Ordinary Bus	4	0	4
Walking/wheelchair	6	0	2
Taxi	7	1	1
Train	5	0	1
Bike	5	0	3
Travelling on own	3	0	4

Making choices at the time of transition for young people with a learning disability

The family car was seen as a preferred mode of transport and dial-a-journey appeared popular. Four were unhappy about travelling on ordinary buses but only 1 indicated he did not like trains. The bike was seen as a positive option for 5 participants and 1 person specifically indicated that he wanted an electric wheelchair. Another participant expressed his dislike of being encouraged to walk as part of a programme to help him lose weight. It was encouraging to see that he had placed riding a bike on the positive axis until he made it clear on the third visit that he had meant a motorbike! Two people added in that they wanted to fly in an aeroplane, as they had never done this.

DISCUSSION:

Talking mats has proved successful in enabling young people with a learning disability to communicate their views. There are a number of advantages of **Talking Mats** that proved to be valid for this client group;

- The **Talking Mats** are simple and enjoyable to use
- Using **Talking Mats** is non-threatening in that there are no right or wrong answers
- The **Talking Mats** framework separates the strands of the issues to be discussed into manageable chunks which assists comprehension
- The use of pictorial symbols assists people with learning disability in processing the concepts to be considered.
- The pictorial symbols can be used to augment the participant's existing communication system or can be used as an alternative to speech
- People with limited hand control and/or those who fatigue easily can use the **Talking Mats** simply by eye pointing.
- The participants can take as long as they require to consider the pictures, select them, move them around and change them until they are satisfied that the final composite picture truly represents what they mean.
- The final pictorial representation can be photographed as a permanent record of the participant's views and used in order to bring about change.
- The participants have ownership of the results and can decide who to show them to (this can be indicated with another 'mat').

Ownership:

Within this study it was made clear to the participants that they had ownership of the mats. One participant expressed some sensitive family issues but was clear that the 'people mat' was not to be shown to anyone else. Some chose to use their mats in practical ways e.g. one participant used his mat to help him be heard at a transition meeting and another persuaded his key worker to get him back into college from which he had previously been excluded. One young man with challenging behaviour has been able to express the reasons for his frustrations and staff found **Talking Mats** a useful method for diffusing conflict. One young man is using the **Talking Mats** in an ongoing way to try to explain his unhappiness since he left school. Most participants were keen for their families and key workers to see their 'mats' and show them what they really felt. Two

Making choices at the time of transition for young people with a learning disability

participants specifically asked that their key worker be present during the interview.

Distractibility:

Given the severity of learning disability for some of the participants there was little difficulty in sustaining interest and we were surprised at how little the participants were distracted. Despite the interview lasting between 45 minutes to 1 hour, and even when interrupted, there was no difficulty in bringing people back to the task. Indeed many expressed how much they enjoyed it some were keen to carry on for longer. Possible reasons for this are that it is not perceived as a test but more of a conversation. The focus on the 'mat', rather than on direct one to one conversation, may also reduce the pressure on people who find verbal communication difficult. The researchers observed that the participants visibly relaxed as they realised that the 'mats' were allowing them to express their views in a meaningful and tangible way where they had ownership of the process, could change their minds and go at their own pace.

Boredom:

The number of factors selected by participants as indoor and outdoor interests made us question why many young people with learning disability are described as being bored and unmotivated. It appears that there are many activities they want to be involved in - none of them unreasonable, excessively costly or impractical.

Sub mats:

The placing of a factor on either the negative or positive point does not explain why it is there and further 'sub mats' to separate out the strands of thought may be required. An example of this was given by one participant who put **library** at the negative end of the **leisure** 'mat'. This surprised his key worker who thought he liked going to the library but when it was explored further by presenting him with a **sub-mat** with 'books', 'story tapes', videos, 'books' etc., it emerged that he did not like getting books from the library but he **did** like getting tapes and videos. This was also true for more sensitive issues. For example, without using a 'sub mat' there is no way of knowing whether the placement of **work** on the negative point was because the young person was assuming his physical disability made work an unrealistic option or because he did not want a job.

Acquiescence:

Acquiescence is often seen as a particular difficulty when trying to obtain the opinions of people with learning disability. This did not seem to be a problem for the participants in this study. It is made clear that the '**don't like**' symbol is a useable option and that there are no right or wrong choices. There is some evidence that acquiescence is most influential when the question is not understood (Sigelman et al 1981). The structured framework of **Talking Mats**, which chunks the information into smaller more manageable components, and the use of pictures to reduce memory load both help people with comprehension

Making choices at the time of transition for young people with a learning disability

difficulties and make the issues easier to respond to. In addition the physical involvement of choosing, moving and placing the pictures all contribute to participants being able to give a negative as well as a positive response.

Issues pertinent at transition:

The 6 issues identified initially through the literature search remained the same following discussion with staff and from the comments of the participants throughout the study. The more specific factors were refined through input from the young people and cannot be easily generalised as they are pertinent to each individual..

- **Accommodation** - although most were happy still living in the family home, several of the participants were in the process of thinking about where they might live.
- **Day placement** - access to college was clearly important and there were mixed feelings about day centres.
- **Leisure** – the participants had clear views about what they wanted to do and what they did not want to do. All of their choices were feasible.
- **People** – the participants expressed clear opinions about the people they want to spend time with and maintaining friendships with school friends was important.
- **Transport** – this is particularly relevant for people who may have additional problems with mobility.

Prerequisites:

All the participants in this study, including those with severe learning disability, were able to use the 'mats' at some level. Enough vision to be able to see the picture symbols is required but the ability to recognise named pictures is not necessary.

It appears that the combination of verbal, visual and tactile clues used together provides a greater stimulus than any one of them on its own. One of the strengths of **Talking Mats** appears to be this use of the picture symbol as a **verbal - visual - tactile signifier**. The word is always spoken, there is always a visual representation and, for those with direct access, there is the physical placing of the picture symbol on the mat.

Any pointing method such as finger or eye pointing can be used to select and position the picture symbols. A reliable method of confirming views, either verbal or non-verbal is also required.

CONCLUSION:

Talking mats has proved to be a powerful tool to allow young people with different degrees of learning disability to communicate their views. The participants in this study were able to indicate their likes and dislikes and to express views about the choices available to them at the time of transition. Some expressed opinions that were not previously known to those caring for them and some raised sensitive issues such as who they wished to spend time

Making choices at the time of transition for young people with a learning disability

with. The 'mats' allowed differences of opinion to be explored and were used as a vehicle for further, deeper discussion. Most important, the participants enjoyed using them and appeared to find them a meaningful and tangible way to express their views.

There is a growing body of evidence that young people with learning disability feel that their voice is not heard at transition planning. During the course of the study we heard of a young person who described her experience of being at a transition meeting, as like being 'invisible'. It is crucial that there is both a tool and a process that allows young people to make independent comment and provides a structure to actively include them in the planning process and in their meetings. **Talking mats** as described in this project is well suited to the task.

IMPLICATIONS:

The findings from this study suggest that **Talking Mats** could be used for young people with learning disabilities in a number of ways:

- To encourage interaction and conversation
- To express views in a non-threatening situation
- To plan activities
- To allow involvement in life planning
- To be used in Person Centred Planning
- To facilitate the young person to give their views at Future Needs meetings
- To explore differences of opinions
- To explore sensitive issues

To resolve conflict

DISSEMINATION:

Findings from this study have been presented at

- Communication Matters Symposium, University of Lancaster 17-19th September 2000
- Children and Young People's Voice and Participation Conference organised by the Stirling University Childhood and Youth Research Group 29th September 2000
- Good Practice in Transition Study day organised by the Royal College of Speech and Language Therapists specific interest group in learning disability (Scotland) 6th November 2000

FUTURE:

Lois Cameron and Joan Murphy have been invited to present at the AAC Study Day in Perth, Scotland in April 2000

The authors are planning to do some collaborative research based on the findings of this study with 2 Australian speech and language therapists.

Two papers are currently in preparation for the British Journal of Learning Disability and Communication Matters Journal.

Talking mats has won the regional award for innovation in Forth Valley and is through to the national finals to be held in Glasgow at the end of November 2000.

Making choices at the time of transition for young people with a learning disability

The Research and Development Committee of Forth Valley Primary care Trust has given pump prime funding to Lois Cameron and Joan Murphy to train staff working with people with learning disability to use the **Talking Mats**.

The authors have had enquiries re. the use of **Talking Mats** in Child Protection investigations with children with disabilities and were involved in a local Child Protection Seminar with Social Services and the Police on 14th November 2000. The 'mats' were well received and felt to have a role in this area of work. The research officer from the NSPCC in London has asked to meet with the authors and is coming to Stirling on 6th December 2000.

The researchers believe that **Talking Mats** is a powerful resource in allowing young people with a learning disability to express their views and plan to produce a video training package for wider use. They are seeking funding to enable this.

Acknowledgements:

The authors would like to thank the following people for their invaluable co-operation and insightful comments; the 12 participants, their carers and speech and language therapists. We would also like to thank the staff at the Day Centres, Housing Associations, and Colleges involved.

Key references:

- Beattie, R. (1999) Implementing Inclusiveness Realising Potential *Scottish Executive Report*
- Jones, S. (1985). The Analysis of Depth Interviews. *In R. Walker (Ed.) Applied Qualitative Research* pp 56-70. Aldershot: Gower Publishing Company Ltd.
- Lloyd, M., Preston-Shoot, M., Temple, B & Woo, R. (1996) Whose project is it anyway? Sharing and Shaping the research and development agenda. *Disability and Society Vol. 11 No.3 pp 301-316*
- Murphy, J. (1998). Talking Mats: Speech and language research in practice. *Speech and Language Therapy in Practice, Autumn 1998, 11-14.*
- Sigelman, C.K., Budd, E.C., Spanhel, C.L. and Schoenrock, C.J. (1981) Asking questions of retarded persons: a comparison of yes/no and either/or formats. *Applied Research in Mental Retardation. 2.pp. 347-357*
- Scottish Executive (2000) The same as you? A review of services for people with learning disabilities
- Young Adults Transition Project (1999)-*Optimum Health Services NHS Trust*