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ACCESSIBLE INFORMATION FOR PEOPLE WITH LEARNING DISABILITIES

An Interactive Qualifying Project Report
Submitted to the Faculty
of

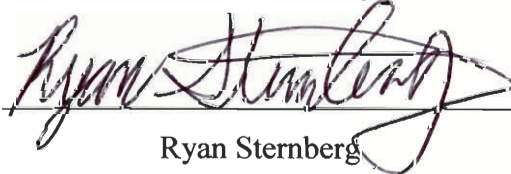
WORCESTER POLYTECHNIC INSTITUTE

In Partial Fulfillment of the Requirements for the
Degree of Bachelor of Science


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August 26, 2003

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Abstract

The goal of this project was to develop guidelines for communication between the London Borough of Merton Social Services and their clientele with learning disabilities. Social Service, health and voluntary workers and managers were interviewed and their recommendations gathered and recorded. The main outcome of this project was a set of guidelines to standardize communication with people with learning disabilities. As a result of this project, communication will be more effective, and the distribution of information will be more uniform.

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Executive Summary

The goal of this project was to develop a set of guidelines for communication with people with learning disabilities in the London Borough of Merton. The need for these guidelines came from the current movement towards modernization and reform in the social service sector in United Kingdom. The London Borough of Merton supports 437 people with learning disabilities, so this movement towards reform is a high priority (Bowman, 2003). The thrust of these changes came from ideas, suggestions and guidance in the 2001 *Valuing People* white paper. In *Valuing People*, the British Government envisions a service based on four main points: rights, independence, choice, and inclusion. To deliver this service, Merton along with other Boroughs in London have called for a person-centred planning approach. The goal of this approach is to have the plan for each person reflect what is important to the individual while giving due respect to their disabilities. The guidelines are not only meant to aid the local government of Merton, but also to help the residents overcome their communication difficulties and participate more fully in their society.

Before creating any guidelines, research was completed regarding what methods, ideas, and techniques were in use in Merton and throughout the world. Several different categories of communication aids were researched: graphical, pictorial, and aural. Graphical representations of ideas were found to express simple thoughts in an efficient and easy to understand manner. Simple graphical representations include signs directing individuals to safe locations if they are being attacked or harassed. Maps of the surrounding area with icons that represent services, can be effective in helping individuals learn about a desired service's location. Pictorial forms of communication are effective in

conveying particular ideas to the viewer. One example of a pictorial aid is the Picture Exchange Communication System (PECS). PECS was created to help teach children with learning disabilities to communicate. A user of the system begins by learning how to make basic requests for the things they would like to receive. This is usually accomplished by exchanging a card with a picture of a toy for the actual toy. Some users go on to develop the ability to answer questions, and learn how to make comments in conversation. Aural communication helps those who are visually impaired to receive and understand information. For example, The Guardian newspaper in London provides a copy of its daily articles on an audio cassette for subscribers who cannot read the normal paper. Another example is a “read-along book”, which features a narrator speaking the information that should be conveyed (Ferrington, p. 1).

The on-site research included gathering further information regarding possible communication types, including symbol sets, Makaton, and audiovisual media. We conducted interviews with a large variety of social service workers, including carers, therapists, and managers. Twenty six unique communication methods were recommended.

The most popular recommendations were:

- the use of Makaton and visual speech, including lip reading and signing, with support from 45% of those interviewed
- the use of pictures and photographs in visual and textual communication, with support from 40% of those interviewed

After talking with Makaton users and members of the Merton Speech and Language Team it was determined that Makaton offered the widest range of options. Makaton

utilizes a combination of verbal communication, and signing. The system also has its own symbol set that can be used when writing.

The conclusions of our research were that:

- repetition, standardization, and patterns are vital for effective communication
- pictures, photographs, or line drawings should be used to aid written communication
- the use of clear large fonts such as **Comic Sans MS** or **Arial** are very important for written documents
- demonstration is a useful technique when working with people who cannot understand symbols/pictures
- knowing the level of your audience's ability to communicate helps to tailor communication techniques for them
- showing respect to the service user and their disability while moving at an appropriate pace allows the service user to get the most out of the conversation

The use of these guidelines will lead to a standardization of communication within the Borough of Merton. All organizations within Merton should follow the same standards for their communication, setting up repetitive patterns that all service users will be able to recognize. This will make all forms of communication, on both personal and group levels, more effective for the average Merton service user. As a result, a greater percentage of Merton's service users will have the information to make informed decisions about their care, and person-centred planning will be enhanced.

1. Introduction

Effective communication is the cornerstone of human civilization. It allows for the exchange of information and ideas, emotional expression and social interaction. Everyday we use a range of means, both verbal and non-verbal, to communicate. There exist many subtleties in language and expression. For people with a learning disability, defined in United Kingdom by a reduced ability to understand new or complex information or to learn new skills, these subtleties are difficult to see and understand. People with learning disabilities have problems with many areas of communication. As a result they miss out on important information and cues that could otherwise help them understand their world more.

The treatment of individuals with a learning disability in United Kingdom has improved in the past century, as societal attitudes toward them have changed. Individuals who had some form of mental impairment were most commonly considered idiots or natural fools (Gates, p. 46). With the invention of eugenics, the term feeble-minded came to be applied to people with learning disabilities. The passage of feeble-mindedness was traced in pedigree charts, and such things as sexual immorality, alcoholism, and criminality were linked to the procreation of individuals with feeble-minds. As time passed and social norms changed, human rights activism increased, and among other things, the Royal Commission on the Law relating to Mental Illness and Mental Deficiency helped create the new Mental Health Act of 1959 (Gates, p. 54). During the second half of the 20th century, significant progress was achieved regarding the treatment of people with learning disabilities.

In 2001 the Parliament issued *Valuing People*, a white paper covering everything from advocacy access to qualifications for people working with people with learning disabilities. It is “based on the principles of rights, independence, choice and inclusion.”(Gates, p. 4) One of the most important ideas that the paper introduced was person-centred planning. The goal of this approach was trying to ensure that the individual wishes and preferences of people with learning disabilities are central to decisions made about them. In order to make informed decisions, people with learning disabilities need to be able to understand the options available to them. *Valuing People* reaffirmed that all offices and departments must have accessible information. Some groups had found symbols and other methods to make their information accessible but the vast majority could not. There existed no standard for communication with people with learning disabilities. As a result, people with learning disabilities were able to access only a small amount of information. Our project addressed the need for accessible information in the London Borough of Merton.

The Borough of Merton, in London, has 437 people with learning disabilities, as recorded by Register Services. Merton Social Services, as well as the Partnership Board, have been trying to provide useful information to their constituents with learning disabilities. For this population, normal verbal and written communication is difficult. One of Merton Social Services’ duties is to communicate rights and services to a population struggling to understand. This was the motivating force behind our project. The goal of this project was to develop guidelines for communication between the London Borough of Merton Social Services and their clientele with learning disabilities.

2. Background

In order to understand what the borough of Merton was trying to communicate, and why it was important that this message be spread, we first had to understand the context in which the borough operates. We needed to understand who this message is being communicated to, and what the difficulties involved in this communication are for these people. Finally, we needed to look at the available methods, both in Merton, and around the world, and tie all these concepts together.

2.1 Defining Learning Disabilities

Every country and many groups have attempted to define learning disability in their own framework. This has led to many different, often confusing definitions of the term.

The World Health Organization (WHO) defines a learning disability in terms of deviation from normal IQ. The degree of the disability is determined by how far an individual moves away from the normal distribution. A severe learning disability would require an IQ between 20-34. A profound learning disability would require a complex additional disability (sensory, physical, or behavioral) that prevents the measuring of IQ.

In the United Kingdom learning disability is defined as “a significantly reduced understanding of new complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development” (Department of Health (DOH) 2001, pg. 14).

Merton defines a person with a learning disability as any person being significantly below average intelligence, having a general long standing delay or interruption in their cognitive development, and who would as a result require help with daily living (<http://www.registerservices.nhs.uk/reports/mertonpld.pdf> pg 70).

2.2 History of Learning Disabilities in the UK

Throughout time there have been a range of attitudes and beliefs towards people with learning disabilities. At some points people with learning disabilities were revered; at other times they were the object of unspeakable dread and fear. The treatment of people with learning disabilities has greatly changed in the United Kingdom over the last few centuries.

2.2.1 Learning Disabilities in the Past

During the middle ages abnormal babies were treated inhumanely and some were put to death. Those who survived childhood were able to live on in the community. Some became court fools, while others played the part of town idiot. Many were simply left to live their own lives and were cared for by members of their family or community. In 1325 De Prerogativa Regis was the first piece of legislation to deal with idiots, natural fools and lunatics. Its purpose was to protect these people's lands when it became apparent that they didn't have the ability to sustain them or use the profit made from them sensibly. Determination of abilities was an important part of the legislation. Several tests were developed throughout the middle ages and early renaissance to determine the level of ability of individuals suspected of having a learning disability. Fitzherbert's test,

developed in 1534, relied on the ability to count out 20 pence, recall names, and tell one's age. Swinburne's test, came into effect around 1591, and relied on an individual's ability to name the days of the week, and measure a yard of cloth. The Elizabethan Poor Act in 1601, the first segregation legislation, restricted the movement of 'unattached' groups including people with disabilities because they threatened the stability of the establishment. It incarcerated them along with beggars, and invalids in workhouses.

(Gates, Chapter 3)

With the coming of the Industrial Revolution, people with learning disabilities came to be known as "feeble-minded." They were singled out as one of the groups that could not sustain themselves in the developing society. As a result when the Poor Law Amendment Act was passed in 1834 they were denied any form of state relief and were again segregated into workhouses. It was also around this time that the idea of eugenics was first developed. Eugenics was the belief in and practice of controlled breeding. It was believed that "the danger lies in the fact that these degenerates [feeble-minded persons] mate with healthy members of the community and thereby constantly drag fresh blood into the vortex of disease and lower the general vigor of the nation". (Tredgold, 1909) A 1904 Royal Commission on the problem of the feeble-minded concluded that individuals suffering from a feeble mind or related problem (ie alcoholism, epilepsy, insanity) were a threat to the stability of British society. Several options for controlling the population of feeble-minded persons were discussed but there were no definite criteria on which to identify individuals who posed a threat and those that didn't. The Mental Deficiency Act of 1913 was the first document that classified people as idiots, imbeciles, feeble-minded persons, or moral defectives. The act was implemented after World War I and quickened

into practice by the Wood Report in 1929. The Wood Committee had been set up to evaluate the education of children with mental deficiencies but by the time the report was released the committee had extended itself to cover the problem of all people with mental deficiencies. The report called for the immediate institutionalization of 100,000 people suffering from mental defects. From this point on, people with learning disabilities were put into institutions with the intention of “correcting” their disability. These institutions were designed to be closed colonies where people with all kinds of mental defects lived and worked together. In 1946 the National Health Service (NHS) Act transferred control of these institutions from the local councils to the Regional Hospital Boards.

During this time research was done into educating the learning disabled. The recognition of the inequalities faced by people with learning disabilities added to the development of the European Convention of Human Rights in 1950. There was no legislative backing to the policies in the convention however until 1959. In 1957 the Royal Commission on the law relating to Mental Illness and Mental Deficiency released what was to become the Mental Health Act of 1959. It was not until the Mental Health Act of 1959 that individuals were allowed to leave institutions and return to society. This act also changed the jargon used to identify people with learning disabilities. The name of mental deficiency was changed to mental subnormality. The *Better Services for the Mentally Handicapped* White Paper, released in 1971, called for a 50% reduction in the number of hospital places and an increase in locally run day and residential care. The Jay Report in 1975 affirmed the need for local authority run care and introduced the concept of normalization to United Kingdom. The concept of normalization was originally intended to mean “an existence for the mentally retarded as close to normal living

conditions as possible” (Bank-Mikkelson, 1980). This definition came under attack several times in the 80s and 90s prompting the re-definition of the term. Normalization essentially replaced the term “social role valorization” which referred to the creation, support and defense of social roles for people at risk (Wolfensberger, 1998). O’Brien & Tyne developed principles of normalization for use when interacting with people with learning disabilities. These principles included community presence, choice, competence, respect, and community participation. In 1989 the White Paper Caring for People confirmed the government’s commitment to the development of locally available health and care services. By 1990 the National Health Service (NHS) and Community Care Act was passed to allow people to stay in their own homes for as long as possible. The 1995 Disability Discrimination Act aimed to protect the rights of all individuals with disabilities.

2.2.2 Valuing People

In 2001 the Parliament released the *Valuing People* White Paper. Its release encourages the continued removal of people from institutions and the use of day centers and residential centers. It also backs the 1995 Discrimination Act, by calling for all government departments to have accessible information, and for all people with disabilities to have the ability to choose what they will do. Areas covered by the paper include a call for increased range of housing and employment opportunities, the development of day-time activities, improved access to health care services, and further development of advocacy services and systems of support. Also called for are the development of a national learning information centre and helpline for carers, the

appointment of health facilitators to support people with learning disabilities in accessing mainstream health care provisions, and the meaningful involvement of people with learning disabilities in the design of services, including the development of a national forum. To help achieve these goals a provision of a Learning Disability Development Fund of 50 million pounds sterling a year was allocated beginning in 2002.

In Valuing People the British government envisions a service based on four main points: rights, independence, choice, and inclusion. The catch all phrase associated with these points is “person centred planning”.

2.2.3 Person Centred Planning

Person centred planning is in the forefront of the Social Services sector. At the centre of this approach is the goal of trying to ensure that the individual wishes and preferences of people with learning disabilities and their families and carers are central to the decision making process. Person centred planning is a completely different way of looking at and working with people with learning disabilities. Its basis is in sharing power and developing community inclusion. Power sharing is important because many people feel they have limited power over their own lives. Other people plan their activities, their meals and more. The goal is to have each personal plan reflect what is important to the individual, his capacities, and what supports he needs. Where person centred planning is used it is very important that the person be involved in the process at every step. It should be the individual's choice to meet. He should have the opportunity to determine who is involved and who isn't as well as have the freedom to discuss his dreams, ambitions, and ideas for the future.

Merton has the responsibility of alerting people with learning disabilities of the new person centred planning approach. The borough has to inform people of their options and make sure that the individual's preferences are respected. In order for this to happen, Merton needs to take stock of their communication needs. These are the needs the team had to address in our guidelines.

2.3 Merton's Communication Needs

Through the borough of Merton there is a wide-range of social services available to eligible people with disabilities who seek out help. "Social Services work with community nurses, psychologists, psychiatrists and other health professionals who support people with learning disabilities" (Social Services for Adults: Services for People with Learning Disabilities, p. 3). The range of services available also includes making arrangements for home care, helping them find employment, making arrangements for housing, even helping them find activities during the day if they cannot work. Social Services makes appointments to evaluate need and does its best to match each person with services that will best suit them. This means that for any type of disability there is likely some form of assistance available through the government of Merton that can aid in easing the burden of day to day living.

A major issue that our communication guidelines must address is that many people with disabilities do not know their rights or the services available to them, and we must be able to express these to them. "People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary" (Valuing People: A New

Strategy for Learning Disability for the 21st Century, p. 23). What this amounts to is that the government feels that people with disabilities have the right to the same basic liberties and freedoms as everyone else in the United Kingdom. The government is dedicated to helping achieve this equality, as is made clear in the British Government's white paper quoted above, and it is understood that people with disabilities have a right to basic assistance and social service. What is most important now is to make people aware of what their rights are, just as it is important to make them aware of the resources available to them, and when these resources change. This is where our communication guidelines must be most robust, because while identifying social services may seem like a simple matter to communicate pictorially or through audio-media, it can be much more difficult to express abstract ideas like 'rights'. This adds a completely different dimension to our project, both in requirements and in the scope of its use.

Besides the important information of rights and services that need to be expressed, we also need to express the less complex ideas, such as meeting times, changes in staff, and other day to day concerns. This requires something other than robustness from our guidelines. It requires our guidelines to have a certain simplicity and adaptability, so that a personal letter from a carer can be just as understandable as a government document talking about a change in health care. It dictates that our system must be applicable on a number of levels, so that people with learning disabilities can be communicated with on both a personal and a group level. It requires us to look at the methods already in use and to augment and support them to create a guideline that will make information accessible to all people with learning disabilities.

2.4 Service Users

There are a wide range of learning disabilities in Merton, and this presents a significant challenge to our project. Merton defines a person with a learning disability as any person being significantly below average intelligence, having a general long standing delay or interruption in their cognitive development, and who would as a result require help with daily living (Bowman, 2003). A person with an IQ of under 70 who also has adaptive difficulties and even learning difficulties is considered a person with a learning disability in Merton.

This means that many of our service users will be unable to read, write, and some may even be unable to understand verbal communication. We must develop our guidelines based on these realities, and with the understanding that people with learning disabilities may, in many cases, also have learning difficulties that add to their communication problems. Thus our system must bridge the difficulties caused by learning difficulties, physical impairments, and the problems caused by a general learning disability. Once again, this is an area where having guidelines that are highly adaptable, that make suggestions for a number of different communication methods, can be truly useful. Without this level of adaptability, it would be impossible to communicate with individuals, and difficult to customize for varied groups.

2.5 Communication Aids

2.5.1 Graphical Aids

Many different methods are available to make intelligent communication possible between individuals.

Graphical representations of ideas express simple thoughts in an efficient and easy to understand manner as well as help clarify complex ideas and the linkages between them. Simple graphical representations include signs directing individuals to safe locations if they are being attacked or harassed. Maps of the surrounding area with icons that represent services can be effective in helping individuals learn about a desired service's location. Some of the icons that would be most important in the case of Merton are indicators of social services provided by the borough of Merton. Other important icons include the locations of shelters, police stations, and food distribution centres. Other ideas, such as using Big Ben to represent government, or a picture of a doctor to represent National Health Services, can help explain to an individual where the communication originates from. These can all be represented using symbols that are familiar and can aid in an individual's understanding, but these symbols must be standardized and used constantly for individuals who need these patterns to make communication accessible to them.

2.5.2 Pictorial Aids

Pictorial forms of communication are also effective in conveying a certain idea to the viewer and are particularly effective with individuals who have difficulty understanding text or speech. Some forms of pictorial communication are designed for adults. *Books Beyond Words* is a collection of stories intended for adults that was

originally created by Sheila Hollins, Beth Webb and Lester Sireling. As of this writing, twenty four titles exist “covering such diverse subjects as epilepsy, abuse, bereavement, depression, making friends, going into hospital, falling in love” (Hollins, 2002). Adults with learning disabilities are involved as advisors and overseers during the creation of the books, for “they monitor the pictures, interpret their meaning and, when necessary, ask for changes to be made until they are satisfied that the illustrations will be clearly understood by future readers” (Hollins, 2002). These books are an effective means of communicating an idea, and each implements a means of expression that can be used as examples when developing other communication methods.

Another form of communication that cannot be underestimated is the use of photographs. In many cases, individuals who have trouble with abstract artwork such as line drawings find colour photographs easier to understand. An example of this is the idea of sending a photograph of yourself in a letter to a person with learning disabilities to help them understand who the letter is from. Pictures can be useful when talking to groups when a video is impractical, and personal demonstrations are not available at the time. It allows a person to communicate through gesture and example even when that person isn't necessarily personally there to do so.

Some forms of pictorial communication were designed to be used with children. Andrew Bondy and Lori Frost created the Picture Exchange Communication System (PECS) that is used today when teaching children with learning disabilities how to communicate. A user of the system begins by learning how to make basic requests for the things they would like to receive. For example, a child may hand the supervisor a card with a toy on it, and in response, the supervisor will give the child this toy. Children

using this process learn how to construct simple sentences, and how to describe things using adjective-like structures including colour, number and shape. Some go on to develop the ability to answer questions, and learn how to make comments in conversation. It is interesting to note that in groups of preschoolers where the system was used, over two-thirds went on to communicate normally through verbal means (Bondy). The PECS system is currently in use in schools for children with learning disabilities, in United Kingdom, including St. Ann's in Merton.

2.5.3 Aural Aids

Aural communication can help those who are visually impaired to receive the information necessary for them to understand the services and rights available to them. Also, some people with the ability to see text or pictorial forms of communication may not understand it, and may need clarification on basic points. Simple examples that are applicable include sound generators near areas of safety that the visually impaired can hear and follow. Combining aural communication with other forms may convey more information than solely relying on aural communication. An example is a "read-along book", which features pictorial images accompanied with or without text, and a narrator speaking the information that should be conveyed (Ferrington, 1994).

2.5.4 Interactive Communication

Sometimes an impersonal voice or a pamphlet with only pictures and words will not convey the intended ideas clearly. Individuals reading the pamphlets may have

questions about the material in the pamphlets. Their questions can be answered, to a degree, by using interactive forms of communication, such as computer programs, as means of presenting information. If a point is unclear, or difficult to understand, the person with learning disabilities should be able to make requests for more information on that subject, or be able to change the complexity of what they are reading. This could be accomplished with relative ease, especially through multimedia communication means.

Another method that must be considered is that of communication through a carer or advocate. One of the main concerns, especially when dealing with asking questions or getting feedback from people with learning disabilities is that in many cases, without personal knowledge of that person's habits, response may be difficult to gauge. This can be remedied by allowing carers to aid in the communication with these people on a personal level, letting them explain complex ideas to each individual. One of the concerns here is that the carer might allow their personal feelings on the matter to influence how they interpret responses, and in this case, it may be appropriate to have an advocate available. The advocate could be trained to understand the communication methods of a person with learning disabilities through a small booklet containing their personal habits and the most effective ways to communicate with them.

When undertaking the design of a communication system for Merton, one must be sure to consider all the options available for use. It must be remembered that we are creating a solution for a very large, diverse group of individuals, each with specific needs.

2.6 Current Developments in Merton

In following the guidelines set up in Valuing People the London borough of Merton has initiated several changes to help empower people with disabilities.

The Learning Disabilities Partnership Board has been created to lead the planning process for people with learning disabilities in Merton. This learning disability representative body discusses issues arising from the Valuing People White Paper and the person centred planning approach and creates plans for their implementation. Topics that the board discusses include creating new housing opportunities for people with learning disabilities, dealing with transition, improving employment opportunities, and health action plans.

Merton has convened a Speak Out Group, consisting of people with learning disabilities, who represent people with learning disabilities at the Partnership Board. The Speak Out group meets every two months and discuss upcoming partnership board topics. This way the people in the group are ready to discuss with the partnership board.

To help people with disabilities in accessing mainstream health care provisions, the borough is integrating the health services and social service departments. By October 1st of this year the two groups will function under one budget and one department head.

Merton finds that “People with learning disabilities currently have little control over their own lives, though almost all, including people with the most severe learning disabilities, are capable of making choices and expressing their views and preferences” (Valuing People: A New Strategy for Learning Disability for the 21st Century, p. 44). Through person centred planning Merton hopes to change this. The borough has set up a person centred planning implementation group, consisting of people with learning

disabilities, carers, advocacy staff, residential and day-centre staff, and people from the provider and voluntary sectors. The group is working on a plan to help facilitate the development of true person centred planning for the learning disabled population.

3. Methods

As we began to develop our communication guidelines for the Borough of Merton, we gathered information about people with learning disabilities from direct interaction with Health and Social Services staff and managers. The background work provided a definition of what a learning disability was. However, the project still lacked the practical aspect of actual contact and communication with people with learning disabilities and their service providers. Thus, a primary source of information for the continuing research had to be people who had every day contact with people with learning disabilities, such as carers and social service workers, as well as people with learning disabilities themselves.

3.1 Interviews

The best sources of information about people with learning disabilities in Merton were social service workers who work with them and for them on a daily basis. The major focus of data gathering for the project became interviews with social service workers. These workers included carers, psychiatrists, therapists, and managers. Many of these interviews were initially set up by the project sponsor, Unity Slade, while some more were scheduled as the project continued and further information became necessary.

The interviews were as unstructured as possible, allowing the person being interviewed enough flexibility to express their opinions without straying from the topic at hand. Each interview began with an explanation of the person's title, what they do, and who they work with. Several short questions were included in each interview, spurring further discussion and highlighting relevant points. This included questions about the

depth of the interviewee's contact with people with learning disabilities, the spread in severity of learning disabilities they have worked with, and what methods of communication they found useful. As our project developed, additional questions about employee training and other aspects of the guidelines that we had developed were worked into the interviews.

This style of interviewing created a certain level comfort during the interviews, allowing the interviewee to express him/herself more freely. This was valuable for the project, because it allowed us to determine which questions would be relevant and explore those questions more deeply rather than ask questions the person could not answer. The atmosphere of our interviews made people much more open about sharing the names and contact information of other experts and organizations as well as resources. Often we were invited back if we should need more information in the future. The limitations of this type of interview were that it occasionally led to anecdotes and data not relevant to the project at hand. It also caused us to need further explanation of topics that were relevant but that the interviewee might not have perceived as such.

One of the most valuable opportunities provided by these interviews was the ability to seek confirmation about ideas we had developed for the guideline. We used the open style of our interviews to get opinions and suggestions about various aspects of the project in development. This allowed us to get opinions from a wide range of social service workers, including people working directly with service users, managers, and therapists among others. This further enabled us to discuss ideas and data gathered in previous interviews and provided an experienced peer-review for some of our data.

Throughout this process, we received a wide-range of written material from various sources. These materials included things like newsletters, textbooks, internal documents about people with learning disabilities, and much more. This data is often easier to read separately and consider for its own merit after the interview instead of viewing it as part of the interview. It allows us to use the material to support our entire project as opposed to using the material to support our data from a single interview.

The general format for our interviews was very simple. Two members attended each interview, took completely separate notes, asked their own questions, and recorded their own answers. This allowed us to compare our notes at the end to find correlation on relevant issues, and discuss reasons why certain points were not included in one or both sets of notes. The third member would either be absent or would observe the interview without taking notes. This third member would then be able to peer-review the data taken and mark points that he or she felt would benefit from further analysis. This acted as a sort of screening process, filtering out outlying opinions and providing room for discussion about the relevance of our interview data. The names of people and groups we interviewed as well as general interview questions are included in Appendices A and B.

3.2 Observation

One of the objectives for this project was to understand and communicate effectively with people with learning disabilities. It was necessary to see the service users in their own environment, their homes, day centres, and meetings, where they would be comfortable and would be most communicative. In our original idea for our methods, we considered doing short interviews or surveys with the service users, but as we began to meet with them, we realized this would be inappropriate. Many service

users are unable to read and would need assistance to finish a survey, which immediately casts doubt upon the data retrieved from that survey. The more able service users are capable of understanding questions and answering in a clear way, but any data obtained in this way would be skewed towards those service users, and may not reflect the needs of people with severe learning disabilities.

It was decided that the best way to understand the communication styles and needs of a person with learning disabilities would be to interact with them on a personal level. Almost every person spoken to on this project has said that the best way to communicate with a person with learning disabilities is to meet them, get to know them, and learn their habits. While this was not possible on an individual level in our available time, it was definitely possible on a group level. By watching how people with learning disabilities interacted with their carers, their peers, and us, it was possible to gauge the general level of communication available. It was discovered that if the majority of people in a group understand a concept, they will help those who do not understand it, and so by reaching the majority of people with learning disabilities, our guidelines could be most effective.

We visited the High Path Day Centre and the Jan Malinowski Centre as well as residences at 5 Birches Close and Riverside Drive. There were many opportunities to observe and interact with people with learning disabilities of varying severity. Some individuals were able to converse through both speech and sign language while others were only able to communicate through non-verbal means such as pushing or gesturing. There were also opportunities to meet with groups dedicated to giving service users a voice, such as the communication group at the Jan Malinowski Centre and the most

recent meeting of the Merton Speak Out Group. Conversations with these groups gave us many excellent ideas in an informal setting, and allowed us to hear what people with learning disabilities had to say.

These meetings were extremely important, because they allowed us to gauge the understanding of our target audiences, as well as get to know them. Throughout this project the fact has been stressed that people with learning disabilities are people first, with the same rights and needs as anybody else. These visits really illustrated this point, showing the difficulty some service users face with communication, and putting forth several ideas with how to cope with this struggle. The most valuable result of these visits was that we got to hear how service users themselves have worked on this issue, and how they have made their own voices heard.

4. Results and Analysis

As was discussed before, the goal of this project was to develop general guidelines for effective communication. Although each interview had some unique points, there were certain topics that came up repeatedly. In some cases, the interviewee had ideas about how things could change, and we could compare and contrast these with other ideas we had heard. In other cases the interview subjects agreed that the topic was important, but had no suggestions of their own. They instead commented on previous ideas, creating an informal review process for important topics. Our observation in the day centers and residences was very much the same in this respect. Often when watching service users communicate, it was easy to see which ideas from interviews would aid in the majority of situations.

4.1 Analysis Process and Findings

Although many of our interviews allowed for this informal analysis, it was difficult to keep track of the support and detractors for each idea without further analysis. The analysis process started with each person who had taken notes at an interview typing up their notes under a series of headings. These headings included Communication Difficulties, Communication Suggestions, Policy Issues, Staff Training, Guideline Suggestions, and a miscellaneous section. These notes would be followed by letter codes, each of which represented a certain interview subject. Notes that were similar or the same as previous notes would be classified together. For example, Figure 4.1 is sample text from our compiled notes.

- A) Riverside Drive - House running under Social Services with 8 residents
- B) Heather Carswell – Community Development Officer – and Rachael McCarthy – JMC Day Center Officer – pre-Speak Out Group discussion
- C) Dr. Sophie Doswell – Clinical Psychologist, assessment and intervention for service users, one on one training with Social Service staff
- D) Kathleen McCloud – Assistant Manager of Weir Road Employment Assessment Centre
- E) Julie Philips – Produces large-scale newsletter for borough of Merton’s Social Service
- F) Observation at the Jan Malinowski Day Centre
- G) Claire Pepperell – Speech and Language Therapist - Symbol Set meeting

Communication Types (Suggestions)

Demonstration and gesture a useful tool when possible (A)(B)(C)(D)(F)
 Standardization, patterns and repetition important for many service users
 (A)(B)(E)(F)(G)

Figure 4.1: Example from the Notes Compilation Completed as Part of Data Analysis

Once an initial screening process was finished, we then entered the notes on communication suggestions into an analysis matrix. This analysis matrix kept track of each idea, noting the number of times someone had supported an idea, and the number of times an idea was refuted. This style of analysis also allowed us to reference back to our notes, find the statement and source, and note other statements from that source. This meant that for any statement, it was possible to quantify the amount of support, as well as review specific communication difficulties found by the interviewee involved.

Table 4.1, on the following pages, is our communication forms analysis matrix. As the raw data collected from the interviews was analyzed, the matrix was updated until all the data had been analyzed. The number of times a given method or technique was suggested was recorded in the occurrences column of the table.

Table 4.1: Example of Analysis Matrix

Communication Forms Recommended	Occurrences
Use BIG WELL SPACED PRINT	1
Do not use acronyms	1
Use simple maps to show the location of services	1
Use pictorial and/or color coded time sheets	1
Use colour in pictures, and as an aid in identifying rooms or classes	1
Give positive reinforcement	1
Use good/bad - yes/no questions	1
Use Video to assist discussion, or demonstration	2
Keep groups small, and have people know each other	2
Listen to people when then try to communicate	2
Use a respectful approach	2
Use a symbol set	3
Play music to calm before and after meetings or when anyone becomes agitated	3
Use the Widgit program (Have training in Widgit)	4
Use clear direct communication	4
Try to use multi-modal communication	4
Communicate at their level	4
Use parent/carer to assist communication	5
Demonstrate whenever possible to help the majority understand	5

Use Audio to assist communication with those who cannot read or understand pictures	6
Use a Communication Profile/Personal Passport	6
Standardization, patterns and repetition are important for understanding a communication system	6
Improved Staff Training is needed	6
Pictures/Photographs are helpful to many	8
Makaton/Visual Speech (lip reading, signing) is one of the best ways to communicate	9

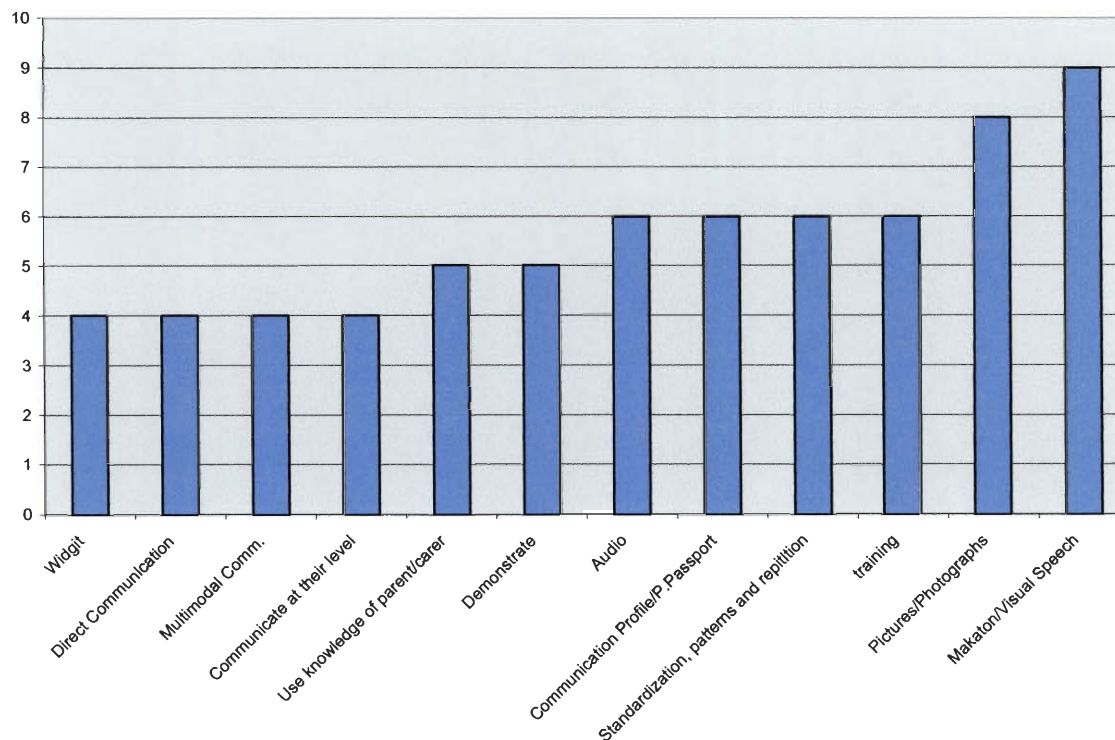


Figure 4.2: Graph of Communication Types That Had Four or More Supporting Comments. Figure 1 is a collection of the more popular communication forms suggested during our interviews. It contains methods with suggestions ranging from four to nine individual supports.

4.2 General Observed Problems and Suggested Solutions

Throughout the data collection and analysis process, several suggestions were repeated that were not directly related to communication. These suggestions would often relate to deficiencies in the communication network, or policies that had been implemented on a small scale, but not on a broad level. Part of the goal of this project was to help Merton to have a single, standardized communication guideline. Many of the policy changes suggested seemed to be centered towards the same goal, with respect to all of Merton's needs. This section is a compilation of the problems discussed, along with suggestions on how to solve them.

The most common problem that we discussed was a lack of communication within Merton services. In many cases, the line of communication would either break down, or was nonexistent. This means that a person working in the Jan Malinowski Centre may never hear of new or interesting ideas coming out of the Employment Assessment Centre at Weir Road. Managers may speak to each other about new ideas, but the chain of communication might end there if the information is not considered important. The best suggestion received for this problem is the creation of a newsletter for all Learning Disability workers in Merton. The staff for the newsletter could be

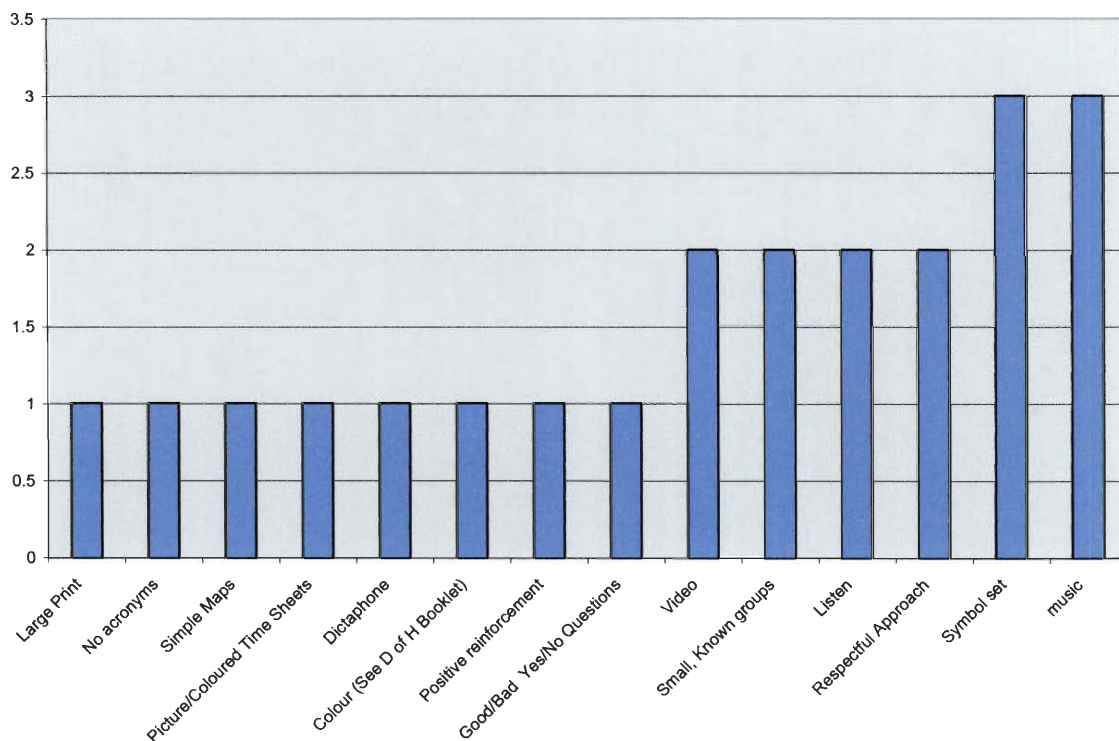


Figure 4.3: Graph of Communication Types That Had Three or Fewer Supporting Comments. Figure 2 is a collection of the less popular, or more obvious, communication forms suggested during our interviews. It contains methods with suggestions ranging from one to three individual supports.

volunteer based, allowing one or two people to have the last 3 or 4 days of the month away from work to compile the newsletter. In this way each day centre, residence, and office could write in about new ideas and accomplishments, and the newsletter could go out to all of Learning Disability Services. This would give people more pride in their work, and give everyone an idea of what is being done in each area. If more information was necessary, then they would know who to contact, and the line of communication would not be reliant on one or two people, but on everyone's combined efforts.

Another problem seen often was the lack of communication between Social Services and other services in Merton. An example of this is the lack of communication between Social Services and Education Services. In many cases, when an individual has to make the transition between children services and adult services, their information at the schools or respite centers where they spent some time gets lost. When discussing this problem with the headmistress of St. Anne's school she explained that the high turnover in Social Services staff caused her to lose contact. One person was delegated to keep contact, and one day that person was no longer there, and no effort was made to keep contact. To help alleviate this problem, it is suggested that Social Service managers re-initiate contact by visiting these places and discussing the reasons why communication is important. It is also important that a secondary contact be there in case the original person is no longer available.

The last problem to discuss is the lack of contact between Social Services managers and the service users. This was a common problem discussed by high ranking Social Service workers who were promoted over a long period of time. They often feel that they have lost contact with the people they are working to help, and because of their

high level of responsibility, it is difficult to find time for this contact. This situation is difficult in many ways, because it is true that the workload at these high level positions makes regular contact impractical. The best way to handle this is, when possible, to create more medium level positions and split this workload between them. In this way, a person may be an administrator 3 days a week, but then spend 2 or 3 days a week working directly with service users. This will not only help managers to feel closer to the people they are working for, but it will also allow them to better gauge the needs and wants of service users. The best way to approach this solution is not to suddenly and dramatically replace the existing system, but instead to do it gradually. Whenever a position opens up, try to find a means of splitting the responsibilities of that position into 2 or 3 positions with less workload, and more contact with service users. This will require training by the Borough both in managerial techniques and effective communication.

4.3 Guidelines for Staff Training

Visits to day centres and residences where Social Service workers are directly interacting with people with learning disabilities allowed us to observe difficulties in communication between staff and service users. Many staff members have expressed feelings that the only way to communicate with someone with learning disabilities is to watch them and get to know them. Until an understanding is reached of the person's individualized traits and habits, effective communication is very difficult. Managers like Andy Ottaway-Searle and communication experts like the speech and language therapy team feel that the high rate of employee turnover in Social Services makes this type of

learning impractical. At almost every location, we have heard that staff needs more training days, and need more opportunities to learn.

One suggestion received from the speech and language therapy team as well as Michael Norman-Smith, services coordinator for Merton Mencap, is that of a personal communication passport. The personal passport is a small booklet comprised of the communication habits of a particular service user. The service user carries the booklet with him. It explains how they like to be treated, how they communicate, and other vital information. For service users with little or no verbal skills these already exist, but they often cover more information than necessary for more able service users. We suggest working with Health and Social Services staff to develop personal passports for service users who have difficulty communicating. In this way, if a new worker joins the staff of a day centre that a person with learning disabilities attends, and has trouble communicating with them, the service user can help the person to understand and communicate more effectively. This will help the new worker to get a head start usually only possible through weeks of confusion, as well as empower service users and help alleviate their frustration due to misunderstanding.

Another suggestion, received from Julie Philips, which has received support from interviewees with similar concerns, was what she referred to as 'cascading champion training'. The idea of this training is that a Health and Social Service worker at a day center or residence would be given a day to take for training purposes, to attend a class or seminar on a specific subject. This worker would then become the 'champion' of that subject for their workplace, teaching other workers the basics and helping when more advanced knowledge is necessary. This allows all workers to receive some training on

the subject, and allows them to decide whether they need more training on the topic. It also allows for an open training schedule, and the ability to filter out information not important to that particular workplace. Lastly, it shows the staff who received the training that there is an investment in their future with Social Services, that they have value individually, and allows staff to improve themselves. Of course, time off and extra authority granted by training might lead to jealousy in the workplace. Certain interviewees suggested it was important to be certain that a different person be trained each time, allowing each person to become an expert on their own topic, and keeping everyone equally involved. This not only improves communication training in the workplace, it also increases morale and sets a mark for incoming workers to strive for.

4.4 Guidelines for General Communication

The goal of this project was to develop a set of guidelines to help Merton Social Services make communication with people with learning disabilities more effective. As this project began, one thing was repeated again and again: ‘The only means of communicating with a service user is to get to know them and their habits’. In situations such as day centres or residences where the rate of employee turnover is high, this sort of intimacy might never be acquired, and even with new employee training, communication would remain difficult. To make communication more accessible to the entire population of people with learning disabilities, we analyzed the communication suggestions of Health and Social Services staff and developed some guidelines. These guidelines are meant to help the Partnership Board to communicate with the majority of people with learning disabilities. In some cases, special effort may still be necessary, but if these guidelines are followed, they will help reduce the difficulty of those special efforts.

During analysis of overall communication suggestions, it was found that the most important task was to repeat patterns as much as possible. Repetition of patterns were found to be important in every type of communication with service users. This includes things like always using the same picture of a tea-cup when signaling for tea-time, always following the same letter formats, and keeping these standards constant. For some users, this may be simply a matter of making things easier to remember and understand. For other users, the constant use of different symbols and lack of patterns may make understanding very difficult, and this may agitate and frustrate the service user. To make certain that patterns are followed as much as possible, these communication means should be standardized by the Partnership Board.

A good example of this standardization should be that all letters should follow the same format. Any written material should be written in large, clear fonts such as **Comic Sans MS** or **Arial**. These letters should be well spaced, clearly formatted, and text should be written at a minimum of font size 14. One should remember to avoid the use of acronyms. Every letter sent should include a picture of the person who sent it, to help remind the user who the letter is from, and to inform them who they should call with questions. As always there are special cases, when these letters are sent by a committee, or by an individual representative of a larger group. In these cases, instead of including a picture of a single individual, or pictures of every member of the group, a symbol to represent the group should be chosen. This can be something as simple as a corporate logo, or a picture of Big Ben to represent government, but it should always make it clear who the letter is coming from.

Formatting is only a small part of making written communication accessible to people with learning disabilities. In some cases service users may have trouble reading, or may have difficulty comprehending large blocks of text. Each new topic should begin on a new line, and should be accompanied by symbols or pictures highlighting the important points. Using color coding can often help to make directions or locations more clear, as can be seen in the Jan Malinowski Centre. Use calendars and clocks to represent the appropriate date and time for an appointment. If the service user is not going to be meeting you, but instead another person, you may want to consider writing the letter on their behalf, and including their picture to avoid confusion. An example of this type of letter can be found in Appendix C.

Symbol sets are another system that needs to be standardized by the Partnership Board as a whole. After meeting with Claire Pepperell to discuss different symbol sets, we recommend the use of the Makaton symbol set, which uses repeating patterns, a tiered learning system and has many different options to make each word as clear as possible. Whenever using symbols, remember that it is important to write to your intended audience. If you are writing to service users who often have trouble understanding line drawings, consider the use of pictures from a source like the Change Picture Bank. If these pictures are too abstract, consider using colorized versions or including photographs representing the same idea. In all cases, avoid overusing symbols or pictures, because at times this may make it more difficult to understand, especially in cases where every single word is represented by a symbol. Instead, only include symbols or pictures outlining the important points, and if you feel the service user may still have trouble understanding, consider using multiple forms of communication.

When multiple forms of communication are necessary, remember that audio is often very effective. Even for service users who are unable to communicate verbally, hearing a voice read along to the words may help make the general meaning clear. For the most part, service users who are illiterate or who have reading difficulties will find a simple audio cassette very useful. For users who have hearing difficulties, or cannot understand audio, the collected data shows that demonstration is one of the most valuable tools possible. When this is not possible, but it is still important that as many people as possible understand the content, consider including a video with demonstrations on it. When speaking to service users with extreme learning disabilities, consider including a letter to their carers or parents asking them to help the service users to understand. In any situation where you are addressing every member of a community, use as many forms of communication as possible to help make it as effective as possible.

It is also important to have certain standards for face-to-face communication, especially for new workers who lack the personal experience discussed earlier. One of the most important standards is the use of the Makaton sign system and gesture when speaking. The Makaton signing system is meant to be used alongside with spoken word, helping service users who have trouble understanding verbal communication, while letting them get used to the sound of the word. It is taught on a tiered basis, and has a direct one-to-one relation to the words available in the Makaton symbol set. The use of even partial Makaton shows a willingness to communicate, and even if the user is unfamiliar with Makaton, the use of Makaton may help ease tensions in frustrating situations. Some users are very adept at Makaton, and may be able to help communication by explaining ideas in a way you had not considered. It is even possible

that in using Makaton regularly, you may inspire service users who have difficulties with verbal communication to learn the system and speak to you with it. These guidelines suggest that training be done in a cascading style, and because Makaton is taught in a series of levels, it seems ideal for this type of training.

If you are unfamiliar with the Makaton signing system or are communicating with service users who cannot understand it at all, there are several options to consider. The first is to keep a small number of communication aids on hand, including pictures or objects that symbolize common or important ideas. An example of this is keeping a picture of a tea cup to symbolize tea time, or a picture of a toilet to ask if someone needs to use the bathroom. Also, remember that one of the most suggested forms of communication is demonstration, so use demonstration and gesture as much as possible to make your point. Always make sure you have the full attention of the person you are speaking to, and when they respond, give them your full attention in return. Remember that communication can be as clear as spoken words, or as subtle as looking down or shifting in your seat, so watch body language carefully.

Whenever addressing a group of service users, try to follow some simple rules to make communication as effective as possible. Keep groups small, and try to make sure service users cover a range of ability levels, and are all somewhat familiar with one another. This will often help cut down on embarrassment, as well as encourage more able service users to help other people in the group. Any demonstrations should be large enough for everyone to see and hear, so consider a video or projected presentation for these times. Move at a pace appropriate to the group, and be respectful of those who have more trouble than others. Set rules for asking questions early on, such as holding up

a placard with a question mark like the Merton Speak Out Group and Partnership Board, and be sure to follow these rules as well. Schedule breaks in your presentation or video for people to make comments or ask questions, and make sure that you never single any one person out for questions. Give positive reinforcement where appropriate, but avoid making derogatory comments that might embarrass one or more service users. Always know your presentation beforehand so you can avoid repetition or contradiction that may confuse the service users.

A few last important points on face-to-face communication deal with respect and understanding. Treat the service user as an equal if possible, and avoid patronizing them, and be respectful to their learning disability. Do not try to force a service user to do anything they don't want to, and if they become agitated or upset, calm things down or consider rescheduling for another time. In these cases, some light music may help put the service user at ease, and may make it possible to continue the discussion in a few minutes. Avoid open questions, and instead try to use good/bad or yes/no questions. This makes it easier for users who can only communicate physically, and helps avoid the problem of a user just saying the first or last option in a list. Try to become as familiar with a user as possible before asking questions or trying to get feedback, either through their carer or parents, or through something like a personal passport. This will help put the user at ease, especially if it helps avoid frustration or misunderstanding.

5. Conclusion and Recommendations

As was discussed before, the goal of this project was to develop general guidelines for effective communication. Although this goal was completed successfully, these guidelines are the means to an end, not the end themselves. In this section, there is an overview of the results, as well as suggestions for further research.

5.1 Conclusions

The original goal for this project, as stated, was to develop guidelines that would aid effective communication, and give a few examples of such communication. As we conducted our interviews and observation, it became clear that this would not be enough to help the Borough of Merton. For example, Social Services management had difficulty communicating among its different branches, as well as with other government organizations and service users. There were also problems with developing a training program for incoming workers and keeping up that training throughout their careers. This meant that in order to help the London Borough of Merton, we needed to consider these needs as well as the need for communication guidelines.

Throughout the data collection and analysis process suggestions relating to deficiencies in communication, or lack of overall support came up repeatedly. To solve problems with internal communication gaps Social Services should consider the use of an internal newsletter for Social Service workers. This would allow different branches of Social Services to keep aware of what other branches were doing, as well as publish their own accomplishments. To solve the problem of communication with other branches of local government, Social Services should choose a representative for each organization,

with another person trained by them to be the next representative. This would mean that at any point, there is always one person to act as a communication liaison between Social Services and those organizations. The last issue discussed was a lack of communication between high level managers and service users. The creation of more positions, each with less responsibility and more contact with service users would help remedy this situation, keeping managers in contact with the people they work for.

Another problem encountered repeatedly was difficulty in helping new staff learn to communicate and a lack of staff training for important skills. To ease the difficulty of learning to communicate with service users, services need to develop a set of personal passports. These passports would include information on communication tactics, special meanings of service user responses, and other important information the service user is unable to express. These passports are already in place for service users with severe learning disabilities, and need to be adapted and developed for all users with communication difficulties. To train staff to use new techniques for communication with service users, Social Services should adopt a system of cascading champion training suggested by Julie Philips. This system would send a Social Services staff member to go and receive training, and then have that worker champion the subject for other workers, training them as necessary. This training allows different workers to receive training and become champions, not only to spread that training, but also to increase their own value at the workplace.

This finally leads to the communication guidelines. These guidelines cover how to make both written and spoken communication more effective. For written communication, it is suggested that Social Services use of big letters, clear fonts, and

expressive pictures to aid communication. It is also recommended to consider multiple forms of communication, like the use of a video or audio tape to help illuminate the information in a letter. For spoken communication, the included guidelines are meant to help both individual and group communication. This includes ideas such as using demonstration and gesture or Makaton signing to help express oneself. Also, it includes guidelines on respecting not just the person, but their level of disability, and how to communicate effectively without patronizing the service user. Overall, these communication guidelines along with the policy and training guidelines should help Merton Social Services to communicate in a more effective manner.

5.2 Recommendations

The suggestions for further research stem mostly from an experience at the Jan Malinowski Centre. At the Jan Malinowski Centre, there is a group of people with learning disabilities who have developed a guide to help new people coming into the day centre. This guide uses the color coded room system, as well as pictures, photographs, and pictorial timetables to help get the new service user adjusted. It includes a video, and is an excellent example of the kind of literature we hope will be produced by these guidelines in the future. Not only is this a brilliant idea for an incoming service user, but the research to create this guide was done as much as possible by service users themselves.

A suggestion for further research is to have a team work with different groups of people with learning disabilities to develop similar material. Instead of creating a small booklet trying to convey difficult ideas to a diverse population from an administrative viewpoint, try to communicate from the service user's viewpoint. This would get the

service users involved and allow them to help as much as possible. The group met at the JMC was enthusiastic and proud of the work they had done, and this not only gives the service user something beyond the normal day centre activities to do, it helps Social Services as a whole. It was impossible to explore this topic more during research because the meeting was unfortunately very late in the interviews, and so there was no time to research the feasibility and scope of such a project. It would still be a very valuable idea for Social Services to do further research, and if this idea proves to be feasible, it could make communication more effective than ever before.

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Appendix A: Scripts and Questions

A.1 Script with Individuals with Learning Disabilities

Thank you for willing to take part in this interview. I would like to take a moment to assure you that everything said or written in this interview will be kept completely confidential.

Can I first ask you what your disability is?

How has your disability affected your learning experience?

Were you in special classes/ home schooled?

Was your learning experience favourable?

Why or why not?

How has your disability affected your ability to get a job?

Do you work?

What do you do?

Does your employer provide accommodations for your disability?

What services have you received?

At school?

At work?

From the government?

From any other agency?

How would you evaluate these services?

Are there any ideas you could recommend?

Any improvements?

Do you utilize any of the resources available through the Merton Disability Office?

If yes: 1) which ones?

2) how did you learn of these resources?

If no: why not?

How would you evaluate these resources?

Are there any recommendations you have?

What would help you to understand the resources and services available to you?

Do you have any questions before we wrap up?

Thank you for talking with me today. Have a wonderful afternoon/evening.

A.2 Questions for Carers

What is the name of the person you care for?

How old is this person?

How long have you been caring for this person?

Are you the primary caregiver?

What is the disability of the person you care for?

Do you utilize the resources available from Dept of Health?

What resources do you utilize?

How do you utilize these resources?

How did you become aware of these resources?

Do you utilize the resources available from Merton Disability Office?

What resources do you utilize?

How do you utilize these resources?

How did you become aware of these resources?

Do you feel you are aware of the resources available to you?

If not, why?

A.3 Questions for the Experts

Please State Your Name?

Please State and Describe Your Position?

What is Your Educational Background?

What is your connection to People w/Learning Disabilities?

How often do you have contact with people with learning disabilities?

What Types of Communication do you find most useful for People w/ Learning Disabilities?

On a scale of 1 to 10, how effective would you rate each type?

Is any type specific to a certain type of disability?

Can you suggest the names of any other experts in this field?

Appendix B: List of Social Services Staff Interviewed

Individual Interviewed	Position Held	Date Interviewed
Brenda McKiernan	Manager at 5 Birches Close	13-May-03
Roberto Sarah	Manager at Riverside Drive	13-May-03
Janet Steinschulte	Marketing Officer at Civic Centre	14-May-03
Heather Carswell	Community Development Officer	15-May-03
Robert Edmund-Searle	Assistant Manager, High Path	15-May-03
Clive Duke	Employment Advisor, High Path	15-May-03
Dr. Sophie Doswell	Clinical Psychologist	16-May-03
Andy Ottaway-Searle	Direct Provision Manager	16-May-03
Nik Crombie, Clare Pepperell, Sonya Blake	Speech and Language Therapy Team	16-May-03
Nancy Adamson	Service Manager Learning Disability	19-May-03
Kathleen McCloud	Assistant Manager, Weir Road	19-May-03
Julie Phillips	Planning and Commissioning Officer	21-May-03
Jan Malinowski Centre	Observation at	22-May-03
Mike Norman Smith	Mencap at Wilson Hospital	27-May-03
Clare Pepperell	SLT Team	28-May-03
Ruth Tinn	Communication Group at JMC	29-May-03
Dorthia Dunkin, Wendy Perez	BBW @ St. George's Medical School	4-Jun-03
Tina Harvey	Head Teacher at St. Ann's School	5-Jun-03
Jackie Jablowski	Merton Register Orchard Hill Hospital	6-Jun-03

Appendix C: Sample Letter

Dear Sir or Madam,



We are students from Worcester Polytechnic Institute in the United States of America.



We have worked the past seven weeks on a project to help Merton Social Services.



We visited the day-centers in Merton and talked to your carers and other workers to learn about how you communicate.



Our project is a collection of rules and guidelines that help people communicate information to you in a way you can understand.



We hope that you will better understand the materials you receive from Social Services.

Sincerely,



David Sonderling



Ryan Sternberg



Catherine White

Appendix D: Quick Reference Guidelines

D.1 Guidelines for General Communication

Use repetitive patterns:

- Same format for all letters
- Same symbols for each word

Write in clear fonts such as **Comic Sans MS** or **Arial**.

Write in large fonts and keep all sentences well-spaced.

Include symbols or demonstration aids to highlight important points.

DO NOT use symbols to represent every word, only important concepts.

Respect the disabilities of your intended audience:

- If symbols are too abstract, use photographs.
- If reader is visually impaired, include an audio cassette or speak.
- If demonstration is necessary and you cannot be there, include a video.

Always make certain you have the service user's attention before speaking.

Listen to what the service user says and watch their body language.

Try to communicate at the service user's level and show them respect.

If you do not know the user, try to involve a co-worker who is familiar with them.

Use Makaton along with spoken word, even with users who may not know Makaton.

Bring communication aids such as photos or related objects to aid communication.

Use yes/no or good/bad questions, avoid open response questions.

In any letters, include a photograph to remind the user who is sending the letter.

Any written sentences should have some use of symbols to highlight important points.

Always use same symbols to represent each idea and avoid confusion.

D.2 Guidelines for Group Meetings

Know the names and faces of the people you are meeting with.

Greet everyone by name, and keep the atmosphere friendly.

Keep meeting groups small, and make sure most people know one another.

Use light music beforehand to ease anxiety about group situations.

Communicate to the general level of the room, but help people with extra difficulties.

Keep everyone involved – let more able service users help less able service users.

Use Makaton when majority of user know Makaton.

Otherwise, use demonstration, power point, or videos to help illustrate points.

Schedule regular breaks for people who may have questions.

Do not single anyone out – distribute questions evenly.

Give positive reinforcement, but do not humiliate anyone.

In any letters, include a photograph to remind the user who is sending the letter.

Any written sentences should have some use of symbols to highlight important points.

Always use same symbols to represent each idea and avoid confusion.

Be familiar with every aspect of your own communication – avoid adlibbing on the spot.

Everyone should follow same rules, service users and Social Service workers alike.

Instead of individual pictures, use a symbol when representing organization as a whole:

- **Big Ben** to represent government
- **Doctor** to represent National Health Services