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# MJOT – Editorial

## *Important Milestones*

The increasing local recognition, visibility and development of our profession can be attested by two significant high points which occurred during the past months. The first important event was organised by the Malta Association of Occupational Therapists in October 2009 and was the meeting of the executive committee of the Council of Occupational Therapists for European Countries (COTEC). One is tempted to harp on the obvious profits, benefits, advantages and gains which this meeting made possible, for example networking with European colleagues. In my opinion this would be overlooking the fundamental value of this event: it is in essence an affirmation of the worth, standing and organisational abilities of the local occupational therapy professional association. With its small resource base MAOT has managed to host COTEC and this is no mean feat. It brings us on equal footing with, and in some instances in a slightly better position than, some very well established local health professions.

I would also like to briefly allude to the other important event which our profession recently spearheaded and which I feel has different implications and values worth considering in some detail. The Depression Awareness study morning organised by the Occupational Therapy Department at Mount Carmel Hospital last November (2009) brought together professionals and clients, and was an excellent platform for promoting services available to overcome the debilitating effects of depression. It was an event steeped in hope and possibility as it dealt with a mental health condition which often mires the sufferer in the bleakest of outlooks. The way in which occupational therapy was portrayed by the participants emphasised the specific contribution of our profession: the value of occupational efficacy and the special benefits imparted by the use of occupation as a therapeutic medium which is ideally suited for the gradual/graded transition to full or alternative participation after a major depressive episode. One could easily appreciate how the profession was being eloquently articulated with various professionals from the health sector and service users.

What was also particularly striking was the extent to which occupational therapy was conveyed in its "natural context", namely occupational practice dealing with occupation. What better way to represent the uniqueness of occupational therapy? Perhaps services in mental health lend themselves to projecting such an image while other practice areas, although of foremost value, fit into a more reductionistic framework or are more challenging to fit into an occupational perspective. If emphasising our profession's unique contribution, knowledge and terminology is still of central importance, I think that the way we portrayed ourselves at the mental health seminar should serve as a template. Prominence and visibility are fine but making other professionals and service users aware of our very special contributions and solutions is still a very relevant goal.

As I write this editorial two more inter-professional events are already scheduled for this spring, one in hand injuries and the other concerning the value of occupation in mental health. This augers well for the profession and is equal to or better than any of our most optimistic forecasts in terms of the potential for marketing and the furthering of the cause of occupational therapy in Malta. It is also good to note that a number of individuals in our profession are proving to be major contributors and prime movers, regularly organising such activities. I applaud them and wish them all the best of luck for future ventures; may their initiative and motivation surge unabated for many years to come.

René Mifsud
April 2010

**The Editorial Board**
**May 2010**

# Perceptions of Staff members on the use of a Biographical approach in the care of Persons with Dementia

This project was submitted in partial fulfillment for the Degree of Bachelor of Science (Honours) in Occupational Therapy, University of Malta, by Rosanne Scerri, in May 2007.

**Abstract**

Biographical approaches offer a promising outlook in the care of persons with dementia. This research study sought to determine the perceptions of members of the interdisciplinary team regarding the use of life story books in the care of persons with dementia. For the purpose of this study, life story books were created for two persons with dementia residing in two psycho-geriatric wards within an institution for the elderly. Consequently these booklets were left available to members of staff involved in their care. Staff members were then interviewed so as to obtain their perceptions on the use of such booklets. Findings indicate that use of life story books led to enhanced person centred care, enhanced understanding of the resident's present behaviour and enhanced communication. Such findings shed light on the importance of using life story work in the care of persons with dementia.

## Introduction

According to the World Health Organisation (WHO), Dementia is a syndrome characterized by a deterioration in higher cognitive functions (including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement) which are accompanied or preceded by a deterioration in emotional control, social behaviour and motivation (Gibson, 2004). However, "the presentation of dementia varies significantly with the individual and the stage of the condition" (Cara & McRae, 2005, p.339). In spite of these individual variations, persons with dementia are often considered as a uniform group of individuals, frequently labelled by care staff as 'confused'. Thus the individuality and uniqueness of each person is often lost (Chandhury, 2002). Use of a person-centred approach to the care of persons with dementia is therefore imperative. One such approach is the use of a Biographical approach. A Biographical approach is one which provides "older people with opportunities, if they so desire, to talk about their life experiences, family, friends, work history, hobbies-often using photographs and personal belongings as triggers to discussion" (Clarke, Hanson & Ross, 2003, p.698).

Life story is a form of biographical work (Clarke et al., 2003). Life story work was defined by Murphy (2004), as "finding out, recording and making use of relevant facts from the individual's life story-past and present" (p. 89). This information can be then recorded in a life story book. A Life Story Book (LSB) is defined by Baker (2001) as "a personalized collection of photographs and other mementos linked with simple text detailing the important events, people and memories in a person's life" (p.185).

The aim of this research project was to determine the perceptions of staff members regarding the use of life story books in the care of persons with dementia. The sections below will give a synopsis of the literature review and outline the three research questions. This will be followed by a description of the methodology, the results and a discussion of the research findings.

## Literature Review

### The Incidence of dementia

As the World's population ages the number of persons diagnosed with dementia is increasing and this is placing increasing pressures on family caregivers as well as on health and social welfare resources (Gibson, 2004). Through the EURODEM study (European community concerted action on the epidemiology and prevention of dementia group), the Malta Dementia Society has estimated a prevalence of about 3500 persons with dementia in Malta (S. Abela, personal communication, March 8, 2006). Due to the absence of published data here in Malta, it is difficult to determine how many of these persons are living in their own homes, in nursing homes or in residential homes. Abroad it is estimated that half of all the residents in nursing facilities have dementia or a related disorder (Gibson, 2004).

In view of the increasing incidence of dementia interventions to improve the care of persons with dementia are necessary. Specifically there is the need for interdisciplinary approaches to the care of persons with dementia (Warchol, 2004). Upon reviewing the literature it was discovered that life story work has actually been put to use by different professionals including nurses, nursing assistants, psychologists, speech language pathologists, social workers and occupational therapists (Baker, 2001; Chaudhury, 2002; Clarke et al., 2003; Gregory, 1997, Haight, 2001, Haight et al., 2003; Haight, Gibson & Michel, 2005, Hansebo & Kihlgren, 2000; Murphy, 2000; Murphy, 2004; Webster & Whitlock, 2003). One common reason for using life story work across all disciplines appears to be its ability to allow professionals to get to know the person behind the dementia.

### Fading identity in dementia

Our story contributes to our identity (Murphy, 2004). Unfortunately persons with dementia may have difficulty relating or remembering their story (Hansebo & Kihlgren, 2004). Thus they can easily become isolated (Haight et al., 2005). Daniel Kuhn (2004) claims that Auguste Dieter, the woman whom Dr Alzheimer first identified as having symptoms of brain disease, was not understood by those persons surrounding her. He claims that:

> *Her potential for living with her symptoms [italics added] was never realized. People in her life failed to understand what she was experiencing and what she needed to cope successfully with her confusing world. They did not appreciate her*

> *need for intimacy, community and meaningful activity [italics added]. They did not believe that their own attitudes and behaviours needed to change to suit her needs (p.266).*

Daniel Kuhn (2004) also adds that unfortunately, although this episode dates back to the 1902, in today's day and age some people are still living in the same conditions in which Auguste Dieter lived. It is therefore obvious that in the face of such a disorder where the person's identity is gradually lost (Kitwood, 1997) interventions need to address this loss and should attempt to help the person with dementia retain and regain a sense of self. Use of a person-centred approach to the care of persons with dementia is therefore imperative.

### Person centred care

It was Dr Tom Kitwood who originally coined the term "person-centred care" and emphasised the necessity to consider persons with dementia as a person first (Kitwood, 1997). According to Kitwood (1997) personhood "is the standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust" (p.8). In fact Kitwood claimed that biographical knowledge is essential in order to prevent the fading of a person's identity. Kitwood stated that when the person with dementia is unable to hold on to his/her own identity due to memory loss, this identity can still be conserved by others who are knowledgeable about the person.

Kitwood (1997) outlined five main psychological needs which need to be met if person-centred care is to be provided in the case of persons with dementia. Two of these needs are the need for occupation and the need for identity. The need for comfort, attachment and inclusion are three additional needs which together overlap in the central need for love and contribute to the maintenance of the person's personhood and thus to the provision of person-centred care.

### Linking biographical work with OT: Conceptual framework

According to Wicks & Whiteford (2003), life stories conform to the humanistic values and assumptions of the OT profession since by using life stories one would be preserving the integrity of the individual and accepting the person's experiences as credible. Yerxa (1983) also holds that adopting humanistic values is central to the OT profession. Burke & Kern (1996) state that life history and narrative data can be useful at each stage of the OT process including evaluation, goal setting, treatment planning and discharge. This view is further strengthened within the OT Practice Framework: Domain and Process (OTPF) which includes the importance of including life history as part of the evaluation process, specifically within the occupational profile. The latter is partly defined as "the initial step in the evaluation process that provides an understanding of the client's occupational history and experiences, patterns of daily living, interests, values and needs." (AOTA, 2002, p. 614).

Various documents were found relating to the specific use of life stories by occupational therapists both in research and in practice (Burke & Kern, 1996; Duchek & Thessing, 1996; Geyla, 1996; Larson & Fanchiang, 1996; Wicks & Whiteford, 2003). All of these articles claim that use of life story work is beneficial in occupational therapy practice. Use of biographical knowledge is especially important when developing therapeutic activity programmes for the person with dementia. Warchol (2004), an occupational therapist by profession, holds that one of the key elements in developing a therapeutic activity programme in nursing homes lies in ensuring that activities are customized to the interests and roles of each resident. In offering generic activities to the person with dementia, it is not surprising that the resident appears detached, bored or exhibits behavioural problems (Warchol, 2004).

**Who benefits from life story work?**

According to several literature sources, life story work has benefits for the person with dementia, staff members and family carers (Baker, 2000; Chaudhury, 2002; Clarke et al., 2003; Hansebo & Kihilgren, 2000, Hansebo & Kihilgren, 2004; Murphy, 2000; Murphy, 2004).

A major benefit of life story work for family carers is that it "reinforces the whole person for family carers/ extended family" (Murphy, 2004, p.95). Additionally life story work can help family carers to see the person with dementia in his/her legitimate role (such as the role of a spouse) rather than as an ill person who needs to be cared for. Life story also offers an activity to do at home and gives the carer a feeling of continued involvement (Murphy, 2004).

Murphy (2004) claims that there are numerous benefits of life-story work for the person with dementia. He holds that it reinforces a sense of identity and self, improves self-esteem, it is a failure free activity, offers enjoyment, reinforces long term memory, helps to maintain/ build relationships with staff members and it reinforces social skills.

Through the use of a biographical approach, many members of staff involved in such a challenging task have reported major benefits. Three major advantages include the provision of person centred care, the role of life story work in understanding the person's behaviour as well as its role in improving communication between staff members and the elderly person (Murphy, 2004).

Following this literature review, the following three research questions were devised in order to answer the above mentioned aim.

1. Does the use of a life story booklet aid in the delivery of person-centred care?
2. Does life story work lead to a greater understanding of the older person's present behaviour?
3. Does life story work affect the communication patterns between staff members and the older person?

## Methodology

### Research design

A qualitative approach was adopted for the purpose of this research study as the aim was to obtain the participants perceptions. After consulting the literature it was found that other studies involved collection of personal life story information over a period of time (Haight et al,. 2003 & Haight et al., 2005). According to Yin (2003), when a case must be studied at more than one point in time, a single case study design can be adopted. Yin additionally holds that use of at least 'two-case' case studies has considerable advantages over the use of a single-case design. Use of two cases would provide the possibility of direct replication and enhance the generalization of findings (Yin, 2003). In view of these findings multiple (two-cases) qualitative case studies using patients with dementia was adopted for the purpose of this research study.

### Context

This research study was carried out within a state-run residence for the elderly. This residential setting was chosen since most of the literature consulted was conducted in such a context (Chaudhury, 2002; Haight et al, 2005; Haight et al., 2003 & Murphy, 2004). Specifically the psycho-geriatric wards (both male and female wards) within this residence were chosen to implement this research study.

### Population and sampling strategies

There were two groups of participants involved in this research study namely the person with dementia and their relatives and the members of staff. Purposive sampling was used when choosing both groups of participants. Persons with dementia who might benefit from this research study were nominated after consultation with professional staff members (the nursing officer and consultant geriatrician) and they were chosen on the basis of the following four criteria:

- the person must have a diagnosis of dementia
- the person must be classified as having mild to moderate dementia. This was determined through the use of the MMSE.
- the person must have relatives who know their life history
- the person must have been in the ward long enough to become familiar with the environment of the ward (approximately eight weeks).

Purposive sampling was employed when choosing members of staff as the researcher chose all those professionals who were directly involved in the care of the person with dementia. A type of purposive sampling called maximum variation sampling was used when choosing staff members. Nurses and nursing aides where selected using random sampling since all the nurses/nursing aides appeared to be involved with the person to the same degree.

### Research Instruments

Three instruments were used during this study. These were the Maltese version of the Mini Mental State

Examination (MMSE), the *'Life Story Interview'*, and a semi-structured interview guide used with members of staff. The *'Life Story Interview'* was devised by the researcher and was based on the *'Personal Life History Booklet'* prepared by Kate Gregory (1997) for Alzheimer's Australia, SA. Australia. Both English and Maltese versions of the interview were developed. This interview was divided into six sections, namely: "My family, Childhood, Adolescence, Young Adulthood, Middle Age and Later Years". A semi-structured interview guide was constructed to be used with all staff members. The interview guide consisted of twelve open ended questions. Both English and Maltese versions of the interview guide were developed.

### Research Procedure

This research study consisted of three distinct stages. **The first stage** involved administering the MMSE to ensure that the residents (chosen through purposive sampling) had mild to moderate dementia. When all participants had given their consent, collection of life story information was initiated by conducting the *'Life story interview'*. The life story interview was conducted first with the relatives and subsequently with the residents. The information obtained was then recorded in a *'Personal life story booklet'*. During **the second stage** the life story book was left in the medical file of the resident for six weeks and members of staff were encouraged to make use of this booklet and the information within it. **The third stage** involved interviewing staff members regarding their perceptions on the use of the life story booklet in the care of the residents in involved.

### Data Collection and Analysis

Analysis of the data was carried out by transcribing the interviews verbatim and consequently analysing the content of the available data. Data included the transcribed interviews and any field notes written on the day of the interview. The data was grouped according to the three research questions. Common themes and sub-themes were then developed from the data.

### Findings and Discussion

In the case of persons with dementia, there were only three persons who fulfilled the criteria outlined in the methodology. One of the persons refused to participate, so that 2 persons (one from each ward) was the final resident sample. Thus, both wards had to be included in the research study as a minimum of 2 participants was necessary. Both participants were considered as having moderate cognitive impairment according to the Mini Mental State Exam (MMSE) score.

Out of the 15 staff members who were selected through purposive sampling, 2 staff members (a care worker and a nursing aide) refused to participate ending with a sample of 13 staff members. These were a consultant geriatrician, two occupational therapists, one physiotherapist, one speech therapist, 3 nursing aides, 3 nurses and one nursing officer.

**Common themes and sub-themes between members of the interdisciplinary team**

| **Research Questions** | **Findings** |
|---|---|
| Does the use of a life story booklet aid in the delivery of person-centred care? | *Theme 1*<br>The resident as a person- An Individual<br>**Sub-themes**<br>I. Increased understanding of the person<br>*II. Changed attitudes towards the resident*<br>*III. Becoming more knowledgeable about the person* |
| | *Theme 2*<br>Engagement in occupations<br>***Sub-themes***<br>*I. Planning individualised activities*<br>*II. Enhancing participation during Occupations* |
| | *Theme 3*<br>Facilitation and continuity of care<br>***Sub-themes***<br>*I. Facilitation of care-giving*<br>*II. Usefulness for non-permanent staff members*<br>*III. Managing transitions smoothly* |
| Does life story work lead to a greater understanding of the older person's present behaviour | *Theme 1*<br>Understanding aspects of the person's behaviour<br>*Theme 2*<br>Dealing with problematic behaviour |
| Does life story work affect the communication patterns between staff members and the elderly person? | *Theme 1*<br>Facilitation of conversation with the residents<br>*Theme 2*<br>Usefulness for communication in later stages<br>*Theme3*<br>Reality orientation |

### The resident as a person- An Individual

Participants in this study claimed that life story work enabled them to look at the resident as a person because they were able to understand the resident more. Additionally they reported changed attitudes towards the resident and that they became more knowledgeable about the person. The outstanding view that life story work enables staff members to look at the resident as a person is consistent with literature from several sources (Baker, 2001; Clarke et al., 2003; Mc Keown, Clarke & Repper, 2006; Murphy, 2000; Murphy 2004).

Several participants stated that they had gained an *increased understanding of the resident* through the use of life story work because it helped them to see the residents in the context of their whole life. One participant stated:

> *When she [the resident] starts saying something about her past, her words might not make sense in that context and at that particular time. However, once you know about her life and what she went through, things start falling into place.*

Chaudhury (2002) and Murphy (2000) also outlined the importance of life story work to empathise with the residents. A number of participants reported *changed attitudes towards the resident*. Changes in attitudes included increased respect for the resident upon knowing their life story and feelings of compassion towards the person. One participant stated, "It helped us a lot because when you start reading you realise that you should respect these persons, like other persons, instead of ignoring what they say".

Additionally one therapist claimed that use of a life story book led her to reflect more on her practice and to a challenge the implied assumption that persons with dementia do not have the ability to improve. This enabled her to be more thorough in her treatment with the residents. Baker (2000), Clarke et al. (2003) and Murphy (2000) also outlined changed attitudes of staff members towards the person with dementia as a consequence of life story work. According to Kuhn (2004), if such changes in the attitudes of staff members occur, the needs of persons with dementia would be more suitably met.

Having access to the resident's life story book led to *improved knowledge about the resident,* according to the majority of participants. One staff member claimed that, "when you see their life history, what they've gone through and the many experiences they had in their life, you can see them more as individuals rather than as patients." Baker (2000) and Hansebo & Kihilgren (2000) also outlined the importance of having a resource of information about the person in order to view the person with dementia more as a unique individual despite his/her limitations.

### Engagement in occupations

Staff members outlined two reasons why life story information allows engagement in occupations. Firstly such information allows for the planning of individually meaningful activities. Secondly it allows staff members to enhance the resident's participation during daily occupations.

The importance of life story work for planning individually meaningful activities according to the resident's previous interests and strengths, emerged from this research study. This is in line with the views of Warchol (2004), Chaudhury (2002) and Heliker (as cited in McKeown, 2006) all of whom outlined the value of incorporating biographical knowledge into care planning so as to develop individualised nursing care plans and activity programmes. It was concluded that participation in meaningful occupations can contribute towards meeting all the five major psychological needs for persons with dementia as outlined by Kitwood (1997). These are the need for identity, occupation, comfort, attachment and inclusion.

Participants within this research study additionally outlined the value of using life story information to facilitate the residents' participation in previous leisure activities, to enhance participation in personal activities of daily living and to facilitate participation during therapeutic groups. The latter two benefits are similar to the views of Hansebo and Kihilgren (2000) and Chaudhury (2002) respectively.

### Facilitation and continuity of care

Three factors were seen as contributing towards facilitation and continuity of care-giving. These were the role of life story work for facilitating care-giving; it's usefulness for non-permanent staff members and its use in managing a person's transition smoothly.

The role of life story information in *facilitating care-giving* was clearly outlined by nurses and nursing aides from both wards. Use of life story work facilitates the challenging task of caring for residents with dementia especially in the case of nurses and nursing aids who spend the majority of time with the resident. One particular nurse stated:

> *If you don't know this person from Adam, how on earth can you deal with your client? I don't understand how they send staff members who do not usually work in this ward to deal with clients of this type.*

According to a number of participants life story information would be especially *useful for non-permanent staff members* who do not know the resident. According to the participants non-permanent staff would find the information more beneficial than permanent staff members who have got used to the resident. Such information should be short and to the point to maximise time management.

All the participants claimed that life story information would help in *managing transitions smoothly* for all concerned. Murphy (2004) also outlines the benefits of life story work as the person progresses through different services. In this way person-centred care would not be limited specifically to the person's present situation. Rather one would be enhancing the possibility that good quality of care is provided according to the resident's needs regardless of the context in which this takes place or the persons who are providing the care.

### Understanding aspects of the person's behaviour

The majority of staff members claimed that life story information helped them to understand certain aspects of the person's behaviour. This result tallied with those of Chaudhury (2002) and Murphy (2004). Murphy (2004) explained how the person's behaviours may reflect his/her previous lifestyle or employment. Similarly several participants in this research study claimed life story work enabled them to understand residents' behaviours in view of the person's previous context and personality rather that attributing them to their medical condition.

One participant stated that knowing about the person's past does not necessarily explain how the person behaves in the present. In fact she explained how one of the residents, an ex-teacher, exhibited inappropriate behaviour by blowing her nose in her dress. This participant attributed such behaviour to a change in the resident's personality because of her dementia. It can be argued that such behaviour might also reflect the resident's inability to communicate her needs. Such inappropriate behaviour might still reflect the resident's need for cleanliness. Staff members need to remember that all behaviour is meaningful (Chapman & Worthington, 2005). Consequently members of staff need to be more receptive to needs that cannot be expressed.

### Dealing with problematic behaviour

Several participants explained how life story information helped them to deal with problematic behaviour. Staff members used life story information to distract the residents when exhibiting problematic behaviour or to attempt to understand the reason for certain behaviours and consequently deal with such behaviours. The latter approach is congruent with the views of Kitwood (1997) who claimed that, "all so-called problem behaviours should be viewed as attempts at communication, related to need. It is necessary to seek to understand the message and so engage with the need that is not being met" (p.136). Problematic behaviours usually reflect feelings of ill-being which can be minimized through better care (Warchol, 2006). More focus should be made on attempting to understand aggressive behaviours, rather than attempting to brush such behaviours away by distracting the residents.

### Facilitation of conversation with the residents

Improved communication was reported by the majority of participants in this research study. Life story information was regarded as being beneficial to initiate conversation with the residents as well as to provide topics for communication. Other literature sources (Baker, 2001; Chaudhury, 2002; Hazel, 1997; Moos & Bjorn, 2006; Murphy, 2000) reported enhanced communication with the residents following the introduction of life story work. Upon using the life story booklet physically with the resident, staff members reported improved communication, enjoyment and improved recall from the resident's side especially when photographs were shown to the resident. This is in line with the study by Clarke et al. (2003) where photographs provoked strong memories from the residents and acted as a talking point between staff members, the patients and their relatives.

**Usefulness for communication in later stages**

Conflicting opinions were obtained on the issue of whether the information would be useful in later stages of the disease. Several participants claimed that the information in the life story book would not be useful for communication in later stages when the residents cannot understand or can't communicate back. However, other participants stated that one can still use the information for communication in the advanced stages. The speech therapist and one of the OT's mentioned the usefulness of life story information for non verbal communication in the later stages. The speech therapist outlines this clearly in the following quote:

> *If you know that somebody, a person, disliked being touched, you won't touch her. Or if you know somebody liked to be touched you might say I'll use hand holding or a hand message or something as a way of getting through to her and communicating non-verbally. A person doesn't cease to be a person just because she can't communicate verbally.*

Hazel (1997) and Nygard (2006) both claim that the non-verbal dimension of language is useful when communicating with persons who have dementia. However from this research study, there appears to be a lack of awareness about the potential of using non-verbal communication with persons who have dementia. This is because several participants did not believe that communication is possible in later stages of the disease when verbal communication is significantly impaired. This lack of awareness may prevent members of staff from being receptive to aspects of non verbal communication in later stages of the disease. According to Warchol (2006), such non-verbal cues, like smiles and groans, can be used to evaluate the quality of life for the person with dementia. Thus, it is important that all staff members are sensitive to such non-verbal cues if the quality of life of residents with dementia is to be enhanced.

## Reality Orientation

Several staff members highlighted the benefits of using life story information during conversation to keep the resident oriented to reality. This is in line with the study carried out by Murphy (2000). However it was the occupational therapists who actually made use of the information formally in this way. Both occupational therapists cautioned about the need to use information sensitively so as not to overwhelm the residents with information. Moreover the consultant, in the same way as Murphy (2004), also outlined the need to avoid using the information to 'quiz' the person about his past. Such a sensitive approach is important as persons with dementia are still capable of experiencing different feelings (Kitwood, 1997). Providing training to members of staff regarding the use of life story work would enhance the probability that life story information is used appropriately.

## Conclusion

The limitations of this study were mostly due to time constraints and, to a lesser extent, because of methodological factors. Several recommendations which can be implemented when using life story work emerged following this research study. Most importantly is the need to improve awareness amongst staff members about life story work, as well as the need to implement a strength-based assessment in the care of residents with dementia. A strength-based assessment is one which couples a life story assessment with a functional cognitive assessment (Warchol, 2006). The role of the occupational therapist in setting up activity programmes according to the resident's previous interests and strengths was also an important recommendation.

It is hoped that this research study has provided some insights into the beneficial effects of life story work in the care of persons with dementia, so that we may optimize the quality of life of this client group. Additionally it is hoped that occupational therapists realise the importance of obtaining knowledge about the person's previous occupations so as to be able to integrate such knowledge in daily occupations, thus enhancing the health of their clients with dementia.

It is obvious that the benefits of placing the person with dementia and his/her relatives at the centre of the team, through a greater awareness of the person's life story far outweigh the limitations of this tool. Life story work (a biographical approach) can be a useful therapeutic tool that can improve the quality of life of the person with dementia, his/her carers and the satisfaction of staff who dedicate their time to the care and well being of the older person.

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# Assistive computer technology used by children with physical disability in educational settings: Perceptions regarding the service delivery process

By Pauline Cassar

**Abstract**

For children with physical disabilities, the utilisation of assistive computer technology has the potential to facilitate meaningful achievements, thus proving to be the turning point in determining a child's productive and independent living. Assistive computer technology has played a major role in compensating for the physical impairments experienced by physically disabled children in various life situations and contexts, thus promoting successful accomplishment in children's typical occupations and developments. Nevertheless, research literature has identified that a number of fundamental elements inherent in the service delivery process, need to be implemented in order to ensure the successful application and integration of technology in the child's life. Hence, this ultimately results in generating substantial improvements in the general quality of life. *OBJECTIVE:* This qualitative research set out to explore the local service delivery process which determines the assistive computer technology needs of physically disabled children. This research study will therefore evaluate the personal experiences of individuals who have undertaken the procedure, to shed light on the resultant benefits and gaps present in the current service being delivered locally.

The following research questions were required to answer to reach the study's aim:

1. What is the process that is currently being followed locally, which provides children with physical disability the required adaptations to computers used in educational facilities?
2. What are the perceptions regarding this service, of professional and non-professional individuals, who have been involved in a service delivery procedure provided locally?

*METHOD:* The study employed a non-experimental evaluation research design, which allowed the gathering of perceptions of individuals who fulfilled different roles in the procedure. The researcher, therefore, was able to explore what comprises the already functioning service and how this, could be amended when the participants' personal viewpoints were taken in consideration. This was possible through the use of semi-structured in-depth interviews, conducted with professional and non-professional participants. The sample consisted of four professionals who are currently conducting AT assessments on different sites, and three parents of physically disabled children who had obtained the required assistive computer technology. *RESULTS:* The data analysis confirmed significant gaps in the current services which are provided locally. The study showed that the various organisations conducting the current process are failing to address a number of critical elements which have been consistently highlighted in the literature reviewed in this study. *CONCLUSION:* This study henceforth concludes that the multiple shortcomings of the process need to be addressed through the founding principles of Occupational Therapy, this being oriented towards an understanding of the child's impairments which hinder accomplishment of activities and life roles.

## Introduction

Throughout the last two decades, many children with physical disability have had the opportunity to successfully participate in educational processes through Assistive Technology (AT). Assistive Technology for computers and an education targeted towards children with disability share a profound relationship: AT has greatly influenced the educational outcomes of children with disabilities while the application of computers in educational settings has led to a greater opportunity for students to meet educational goals, both in typically developing children and children with disabilities.

The application of assistive computer technology can influence a vast number of limitations that the child with physical disability may experience at school with the result of substantial educational gains and fundamental life skills. All this however, is only possible if an appropriate service delivery process is implemented, thus ensuring a compatible fit between the child's needs and the device. Inherent to an appropriate service delivery process are specific factors that need to be addressed pertinently so as to ensure a successful selection, acquisition, and use of the assistive device. Thus, through the use of assistive computer technology, the child with physical disability not only improves academically, but also demonstrates a marked improvement socially, emotionally and in the child's general quality of life.

## The local situation

Disability and its inclusion in society has been a predominant issue in most countries around the world, including Malta. As occupational beings, disabled individuals like all other human beings, have an innate need to use and organise time, space and materials purposefully to gain satisfaction and well-being (Wilcock, 2002). In Malta, much attention has been directed towards the promotion of this idea, that is, inclusion of disabled children in educational facilities.

In the Inclusive and Special Education Review Report (Spiteri, Borg, Callus, Cauchi, & Sciberras, 2005), it was highly emphasised that Maltese schools were to provide, to the most possible degree, environments and strategies which would enable children attending school, to equally participate in activities. Likewise, this shift in focus towards inclusive educational facilities was acknowledged in the: Special Education in Malta (Bezzina, 1993); the National Minimum Curriculum (NMC, 1999); as well as in the Creating Inclusive Schools document (2002), which attempted to provide guidelines for the successful implementation of the NMC. These documents encourage the fostering of inclusive educational settings and attempt at increasing awareness regarding human diversity.

Unfortunately however, to this very day, this idea is still in its early stages of accomplishment. Despite their potential to improve and participate in standard activities, were they to be given the possibility, the measures that were taken so far are not addressing with effect the problems of students with disability. The Inclusive and Special Education Review Report (Spiteri, et al., 2005) has highlighted recommendations which are considered as potential solutions towards the implementation of a successful plan of action: the application of Assistive Technology for computers is considered as one method to constructively influence this issue.

Presently, there are a number of organisations working individually, involved in recommending assistive technology which would assist a child with physical disability to enhance functional performance at school. Operating in collaboration with the National Commission Persons with Disability (KNPD), the Foundation for Information Technology Accessibility (FITA), a local organisation, guides individuals with disability to access computers, whether the latter are used at the work site, for educational purposes or any other functional outcome. At present, FITA employs one IT specialist and one ICT officer trainer who are providing the foundation's services.

The Special and Inclusive Education Network working in collaboration with the founding partners, the ICT Department within the Education Division, further launched a new unit last October – the Access to Communication and Technology Unit (ACTU). Although still in its initial functioning, the main specialty of the unit is to conduct assessments in order to provide recommendations regarding AT devices, thus empower students to access the curriculum and ultimately enhance their quality of life. Being newly launched, the ACTU is administered by one professional; a graduated teacher with a special interest in Alternative and Augmentative Communication (AAC), who provides support services for parents and professionals. The unit's ultimate aims are to enhance the resources to provide its services to all Maltese schools and thus be able to ensure that all students are given the necessary support, particularly with regards to communication skills.

Another organisation which is known to assess children with disability to determine assistive computer technology needs is San Miguel Special School. This special school has learning support assistants responsible for the recommendation of devices and providing guidance to parents along the process.

## CONCEPTUAL FRAMEWORKS

### A Framework for OT

The OT Practice Framework: Domain and Process (AOTA, 2002) recognises that engagement in meaningful and purposeful occupations contributes to the well-being of every individual. Indeed, the ability to perform in daily activities that are deemed important is what gives value to life. This is what Occupational Therapists address in order to greatly influence human performance and the client's general quality of life.

As the framework delineates, education is considered as one of the performance areas of the child's occupation. Children's lives are mainly dominated by this area which is crucial for their overall development. If this fundamental area was to be jeopardised due to disease or disability, OT could offer a means of restoring functional performance. When a disabled student finds the alternative manner to achieve a desired activity, his/her potential, motivation, and performance, flourish and greatly develop. Such benefits could only be achieved if functional performance in educational occupations is viewed in relation to the acquired performance skills, the child's contexts and the activity demands which are placed upon completion of the task. Along these lines highlighted by this framework, the application of assistive computer technology can be successfully designed to foster the disabled child's participation and support development at school.

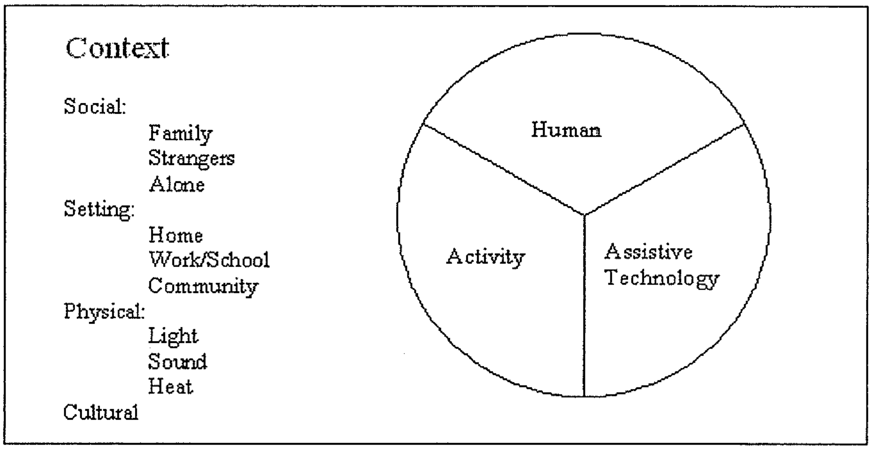
## A Framework for Assistive Technology

The application of Assistive Technology is complicated since there is no one solution for the spectrum of problems and various possible needs of any one client. The model is consequently intended to guide the Assistive Technology Practitioner (ATP) to recommend assistive devices which meet the specific needs of every individual with a disability, ensuring that it is coherent with the person's skills and contexts encountered in daily life. The HAAT Model considers human performance as highly fundamental, focusing primarily on achieving functional results, thus assisting the individual to achieve the desired activity. The model depicts AT as being part of a synergistic system of three other components which determine human performance, these being, the human, the activity, and the context. Each of the components plays a unique part in the system, through which one inevitably influences the others.

The system integrates these four linked components into an interconnected whole. The assistive technology system primarily finds its beginning due to a person's need to independently perform an activity. Every particular activity is carried out in a specific context as deemed appropriate by the individual. Whenever the individual lacks the necessary skills to achieve the activity in its usual context, AT could be used as an enabling tool since the skills required to operate the device are adapted according to the individual's abilities.

The following is a diagrammatic representation of the HAAT Model:

FIGURE 1.1: THE HUMAN ACTIVITY ASSISTIVE TECHNOLOGY MODEL



(Cook & Hussey, 1995)

**Assistive computer technology: The benefits**

In the last decade, the giant leap seen in computer technology has created a new potential for children with disabilities to successfully achieve developmental goals and milestones similar to what other children experience (Judge, 2001). The child who would previously have been unable to use a computer, is now able to access it through specialised computer applications, namely specialised hardware and software (Bain & Leger, 1997). Children with disabilities are thus able to harness computer technology to enhance their independence and become active participants in school activities.

The accessibility of a computer has the dual purpose of obtaining a functional outcome and enhancing the development of skills, whether these are motor, sensory, cognitive or social skills; thus the child experiences the consequences of these actions. Computer manipulation works towards filling the gaps experienced by the child with disability, making it possible for him/her to function in a setting similar to any other typical child (Huntinger, Johanson & Stoneburner, 1996). Computers have additionally demonstrated the remarkable ability to ameliorate the experiences that children with disability gain from school.

For the child with physical disability, it is vital that the environment in which skills are acquired is conditioned and modified in ways that enable him/her to participate more fully in developmental processes (Copley & Ziviani, 2004). The employment of assistive computer technologies in educational settings has been one of the methods through which environments were conditioned to meet the disabled child's needs and thus ensure successful academic and functional outcomes.

The AT devices for computers become the medium through which the child functions as a regular participant in the classroom setting, hence making his/her inclusion and independent learning possible (Struck, 1996). The mastering of tasks, the ability to make choices and the direction of one's own care through the use of AT devices for computers is considered as a principal contributory factor towards self-esteem, self-determination and a marked increase in motivation (Reed & Kanny, 1993). Having acquired more control over one's actions and the environment, the child is more likely to become responsible for his/her own learning experience and avoid learned helplessness, which is often brought about by embracing a passive role. Vygotsky (1997) clearly maintained that an essential feature of learning is the advancement in a variety of internal developmental processes that are able to operate only when the child interacts with people in his/her environment and in cooperation with his/her peers.

**The services delivery process design**

In order to address the multiple facets of the individual's AT needs, the service delivery process ought to be guided by a systematic assistive technology system. Each assistive technology system is uniquely configured to meet the individual's needs, making use of his/her skills and abilities. Various literature (Cook & Hussey, 1995; Bain & Leger, 1997; Copley & Ziviani, 2005) show that a systematic design towards service delivery procedures as well as an AT model enhances the outcomes of successful AT decision-making. Cook & Hussey (1995) and Bain & Leger (1997) state that regardless of the individual's needs, there is a basic procedure to which all service delivery processes should adhere. The following is a diagrammatic representation of an amalgamation of the major steps identified by both models, facilitating a systematic service delivery procedure:

| STEPS | ACTIONS |
|---|---|
| 1. Referral and Intake | At this point, the consumer or someone close refers the case, since s/he recognises a need for AT. The purpose of this phase is to (1) gather initial information, and, (2) tentatively identify possible services required. At this stage it is important to determine who will provide funding services. |
| 2. Needs Identification | A more detailed specification of the consumer's assistive technology needs taken in relation to the consumer's life roles. Through this step, the person's needs and goals are identified, providing a basis for assistive technology intervention. This is considered as one of the most critical components of the process since it is the cornerstone for measuring the effectiveness of the outcome. |

| | |
|---|---|
| 3. Identification of consumer's abilities | Becoming aware of the consumer's physical, cognitive, and sensory skills and limitations. The physical skills evaluation determines the most functional position for individual, of which the most basic is seating needs. Cognitive skills assessed through practical observation. |
| 4. Identification of possible AT devices | The team should determine what AT devices would address the consumer's needs, goals and abilities. Life roles and consumer's expectations need to be taken into consideration. Consideration should be given to present and future environments. |
| 5. Interface between consumer and AT device | Based on the previous four stages, the consumer should be given the chance to experience all possible AT devices and assess accordingly. For the system to be accurate, AT must be integrated with relevant equipment and tried in all possible environments in which it will be used. A time consuming stage, but one which will guarantee that device chosen will be used. |
| 6. Recommendation of device | This stage occurs after achieving a good match between client's needs and AT device. Recommendations should be documented with a detailed report of assessment and achievement of goals through recommended device. |
| 7. Training consumer to use device | Provide the client with written and verbal instructions on its use, care, maintenance, and contact numbers for repair services |
| 8. Periodic re-evaluation | Changes can occur at many levels of the AT system, making periodic re-evaluations a necessity. |

(Cook & Hussey, 1995; Bain & Leger, 1997)

## Fundamental factors in the service delivery process

The service delivery process involved in choosing the AT device is complex, and requires specific factors to be included as a guide. The complexity of such a service could be attributed to multiple aspects, of which, the most important is the tremendous growth in the availability of technology, which leads to an infinite selection of devices. Another influential factor is the paradigm that guides healthcare professionals to view each individual holistically alongside his/her own abilities, difficulties and needs. These two issues, when taken into consideration concurrently, create a bigger challenge to match a compatible fit between the child's needs and the appropriate device.

A review of the literature (Post, 1993; Zabala et al, 2000; Lahm & Sizemore, 2002; Watts, O'Brian & Wojcik, 2004; Copley & Ziviani, 2005; Parette, Huer & Scherer, 2005; Copley & Ziviani, 2006; Gatt, 2007) strongly supports the fact that there are specific factors which influence the outcome of the service delivery process. Despite the potential benefits of AT, there will be an increased possibility of shortcomings in AT application. The factors that are considered to be the most fundamental to the service delivery process are assessment issues, use of a team approach, family involvement, and funding issues.

The occupational therapist is competent in conducting a comprehensive assessment since the foundations of the profession uniquely guide the therapist to view every individual holistically. The therapist's insight into the child's daily occupations, components required to carry out specific tasks, and the contexts in which tasks are carried out, make the occupational therapist the ideal specialist conducting the AT service delivery process (Shuster, 1993; Struck, 1996). During the evaluation process, the occupational therapist is able to take into consideration the components traditionally assessed, such as sensory, motor, cognitive, perceptual, and psychosocial; in so doing, the therapist determines the basic limitations of the child. These limitations are concurrently analysed with other aspects in the child's daily routine such as placing of equipment, positioning of the child, classroom activities, environmental restrictions, funding issues, acceptance of the device, parental concerns, feasibility of repairing the device if necessary, and various other issues that may arise.

Despite the fact that every delivery process of AT has its own characteristics, the occupational therapist's unique ability to evaluate thoroughly the child's capabilities and needs, ensures that a compatible fit between the child's needs and the device is achieved.

## METHODS

### *Participants and Sampling Techniques*

The aim was to have a sample consisting of subjects who participated in the service delivery process of assistive computer technology for physically disabled children. Due to the nature of the roles assumed by the two groups, it was decided that the target population was to be divided into two categories. One group incorporated professionals who are currently participating in service delivery processes of AT provided locally, thus including assistive computer technology for children with physical disabilities attending primary schools. The other group consisted of parents of children with a physical disability who obtained the assistive computer technology.

Being a relatively new service offered in the Maltese Islands, the population of professionals working in the specialised area of AT provision and the parents who have received such services, is a limited one. For this reason, a sample of convenience was chosen since the subjects who participated in this study were selected purposefully rather than randomly, utilizing a technique known as Criterion Sampling (Talbot, 1995). This sampling technique involved selecting all cases that satisfied established criteria in order to enhance the quality of the sample chosen.

The inclusion criteria that determined the sample population were as follows:

1. Parents/guardians of children with physical disability attending any primary educational facility, i.e. either a public mainstream school,

or a private school, or a church school, or a special school.

2. Parents/guardians who have obtained assistive computer technology devices which are used by their physically disabled children in educational facilities.

3. Clients who were referred during the period between January 2005 and August 2005, ensuring that the assistive computer devices were at least used for 6 months or over.

4. Professionals who are involved in the service delivery process of assistive computer technology for children with disability.

The total population of parents who met the inclusion criteria and were thus eligible to participate in the study amounted to four, out of whom one refused to participate due to personal reasons. The selection criteria allowed a total sample of four professionals who are currently involved in the provision of service delivery processes of AT for children with physical disability. These are represented in the following table:

TABLE 3.1: PROFESSIONAL INTERVIEWEES

| PARTICIPANTS | PROFESSION | ORGANISATION |
|---|---|---|
| Participant 1 | IT specialist | FITA |
| Participant 2 | Learning Support Assistant | San Miguel Special School |
| Participant 3 | Alternative and Augmentative Communication Specialist | San Miguel Special School |
| Participant 4 | Teacher | ICT Department within the Education Division (which works in collaboration with the ACTU) |

### Research Instruments

The qualitative information obtained in this study was gathered through an interview. The interview schedules followed the classical format of exploratory semi-structured in-depth interviews, thus ensuring that the participants express their perceptions in a less structured and systematic manner (Oppenheim, 1992; Stein & Cutler, 2000). A set of questions were planned beforehand, allowing significant considerations to the research questions, thus allowing the researcher to maximize the gathering of pertinent information critical to the study. These questions were phrased in an open and non-directive manner about the issue that the researcher requested the participants to describe. Any unexpected responses gathered were followed up with questions that were constructed spontaneously according to the subjects' initial responses. Special attention was given to the wording used with the two different groups of participants. Specific complicated terminology was avoided with parents in order to put them at ease and ensure full comprehension.

The interviews were conducted by the researcher, in a time and place that was most appropriate and convenient for the participants. Before every interview, the interviewees were given an outline of the interview procedure. The interviewees were reassured and helped not to feel embarrassed or disturbed about expressing their perceptions of any situation, since their insights were highly valuable for the purpose of the research. The researcher did not take written notes during interviews, in order to allow complete attentiveness to the interviewee's responses and to assist the interviewee in expressing him/herself in order to avoid a possible block in communication. Every interview was henceforth recorded on audio tape after the participant's permission to do so was obtained.

### Data Analysis Method

The information obtained on the audiocassette was transcribed verbatim, enabling the researcher to thoroughly analyse the data. About one hundred hours were allocated to transcribe seven interviews from the audiotape. These were duly translated from Maltese to English. To ensure authenticity and reliability, every transcription was checked. The audio-recording was listened to once more and correction was done wherever necessary. This prepared the data for subsequent analysis.

Thematic analysis (Talbot, 1995) was the preferred method used to analyse the transcripts. The technique involved thorough reading of the interview transcriptions and the highlighting of keywords in order to establish the main themes. Each theme was assigned a colour code, and subsequently the transcripts were re-read so that their contents were colour coded accordingly. In order to ensure that similar findings were grouped together within the pertinent theme, every part of each transcript was cut and pasted on a separate document under the heading of its relevant theme. Finally, all the themes were cross-checked to ensure that all the information provided had been coded accordingly. This ensured a good presentation of the whole situation. The results were reported in detailed prose, quoting parts of influential and significant data to further support the findings.

## RESULTS

Through Thematic Analysis (Talbot, 1995), common themes and sub themes were established in the textual data. These textual themes and sub-themes were then analysed in order to identify similarities and differences. Findings were reported in the prose form, quoting extracts to further support outcomes. The following are tabulated representations of the themes and sub themes which emerged:

## TABLE 4.2: EMERGING THEMES

### PROFESSIONAL PARTICIPANTS

- Theme 1: Roles undertaken by Organisations
- Theme 2: The Service Delivery Process
- Theme 3: The Assessment
- Theme 4: Trans-disciplinary Teaming
- Theme 5: Funding Sources and Related Issues
- Theme 6: Barriers that hinder the service delivery process

## TABLE 4.3: EMERGING THEMES

### PARENT/NON-PROFESSIONAL PARTICIPANTS

Theme 1: The Service Delivery Process
  *Sub-themes:*
    *i. The availability and need for the service*
    *ii. A review of the process*
    *iii. Assessment Issues*
    *iv. Perceptions regarding team approach*
Theme 2: Perceptions regarding Family Involvement
Theme 3: Funding Issues
Theme 4: Barriers that hindered the service delivery process
  *Sub-themes:*
    *i. Professionals' Attitudes*
    *ii. Lack of Resources*

Respondents' perceptions regarding the service delivery process they experienced constituted the main results in this study.

The themes that emerged subsequent to the analysis of the data were numerous since multiple questions were asked and subjective perceptions were gathered.

The following is a representation is indicative of the themes that emerged from this study: the corresponding professionals' and parents' viewpoints were compared accordingly as shown.

## Summary of Results

*FINDINGS: Professional Participants*

**Theme 1: Roles undertaken by organisations**

Respondents interviewed were asked regarding the roles of each organisation during a service delivery process. Every professional outlined the roles that he/she addresses during such a service. The replies obtained from the participants evidently demonstrate a role common to all the three organisations - providing recommendation to obtain the appropriate device for the child's needs.

**Theme 2: The Service Delivery Process**

In this theme, the IT specialist, the learning support assistant and the AAC specialist gave an account of the service delivery process that is currently being followed in their respective entity.

This theme distinctly illustrated two aspects common to every service delivery procedure highlighted by all three professionals, namely, the assessment stage and the process of obtaining financial assistance.

**Theme 3: The Assessment**

The replies exemplify a substantial amount of overlap between the assessments that are conducted by the IT specialist and those carried out at San Miguel Special School. During the analysis of data, it became clear that similar principles are guiding the professionals during assessments and, consequently, there is an extensive overlap in roles.

The IT specialist stated that the assessment procedure incorporates various aspects, all of which help in determining the specific needs of the child. A typical assessment for a disabled child attending school focuses upon obtaining data about the child's functional performance. Similarly, the AAC specialist mentioned inherent factors in every AT assessment that is carried out at San Miguel Special School. Amongst these, the ones that were considered as most crucial for an appropriate device choice were the child's positioning, the access methods used, and the experimentation on various equipments.

**Theme 4: Trans-disciplinary Teaming**

In view of the replies obtained, this theme outlines the lack of cross-collaboration between the organisations, and the lack of a multi-professional team approach. It was evident that most of the professionals interviewed acknowledged the concept of the importance of a team approach in the AT service delivery processes as well as the failure of applying this concept in the local scene. The AAC specialist specifically stressed the importance of adopting a trans-disciplinary team approach, which enables the pooling of more ideas from various professional paradigms.

On the other hand, the replies obtained from the IT specialist were somewhat different than the ones just discussed. As the IT specialist explained, only two IT-based professionals are responsible for conducting the assessment and providing recommendation during the service delivery process carried out at FITA. The IT specialist considered the liaison with the organisations providing funding as team involvement. However, the organisations providing funding assistance are only involved once the device has already been selected. The learning support assistant also demonstrated an individualistic approach towards determining the child's needs during the service delivery process. In cases where the learning support assistant finds difficulty in finding an appropriate fit between the child's needs and the device that would cater for his/her requirements, liaison is carried out with the CDAU:

*The concept of a trans-disciplinary team approach is not being successfully put into practice in any service delivery process discussed.*

**Theme 5: Funding Sources & Related Issues**

This theme illustrates two common funding sources mentioned by all professionals interviewed, mainly: the Malta Community Chest Fund and the National Commission Persons with Disability (KNPD). The IT specialist, the AAC specialist, as well as the learning support assistant stated that through these main funding sources, parents can opt to submit their request for financial assistance in both foundations.

**Theme 6: Barriers that hinder the service delivery process**

This last theme from this section will bring to light the various barriers that hinder the service delivery process currently provided. Amongst the multiple hindrances highlighted, three were common in most replies; namely, the lack of human and financial resources, the lack of awareness, and attitudinal barriers.

This section has provided a clear outline of perceptions and factors from the professionals' viewpoint. The next section contains the results and the analysis of the data gathered through interviews conducted with three parents. The results focus upon the parents' experiences and perceptions regarding the service delivery process they were involved in.

## *FINDINGS: FAMILY MEMBERS*

**Theme 1: The Service Delivery Process**

*i.* *<u>The availability and need for the service</u>*

The replies ranged from the parent's own interest in becoming actively involved and well-informed, to being passive receivers of services. None of the three parents interviewed had a common source to inform them about the availability and need of such services.

*ii.* *<u>A review of the process</u>*

The three processes that were described by the participants were all considerably different from one another, irrelevant of the specific needs of each child. Notwithstanding the fact that all the three processes followed a different sequence, nevertheless, the description of each service delivery procedure highlighted factors common in every account. One of the most significant issues emphasised by every subject was the reimbursement of money and availability of funds.

The two primary organisations mentioned by all the three participants were The Malta Community Chest Fund and the KNPD. It was commonly agreed that the two organisations offer a sum of money independent of each other's decision as to how much money should be allocated for any one case.

*iii.* <u>*Assessment issues*</u>

Out of the three procedures that were looked into, only one of the subjects, said that the child was specifically assessed to determine his AT needs. The assessment had primarily started by a learning support assistant, who thoroughly reviewed previous IEP reports carried out at an inclusive setting. The participant claimed that the actual AT assessment was a continuous process which took place over a period of time.

The other two participants' reviews of the assessment stages were very similar to each other, since both were conducted at The Eden Foundation by a physiotherapist. These two subjects stated that their children had started working on the assistive computer technology devices long before they were advised to purchase them. The process however, was not a formal assessment utilised to determine the AT needs of the child, but rather part of the therapy program.

*iv.* <u>*Perceptions regarding Team Approach*</u>

Participants were interviewed on their opinions about to what extent team approach had been adopted during the service delivery process. The findings for this matter showed that none of the three procedures adopted a trans-disciplinary team approach.

One other issue that was discussed was the lack of team approach amongst professionals working in two particular inclusive settings. Both parents commented about the barriers they faced when their children still attended an inclusive setting, wherein they attempted at communicating their children's needs to the professionals in charge.

This theme distinctly demonstrates the variation in the service delivery processes that are being carried out locally. Various organisations are recommending the purchasing of assistive computer technologies, since a common source specialised in providing such services is not operating locally. Consequently, the processes that each organisation adopts vary, due to the fact that there are no standard principles guiding the services.

### Theme 2: Perceptions Regarding Family Involvement

Participants were asked to give their opinions about the importance of the family members' involvement during the service delivery process. The replies evoked two issues common to all three responses.

The first issue that the participants commented upon was the importance of the family's involvement in expressing the child's needs to others. The subjects argued that they, as parents, know their children better than any other individual, irrelevant of the professional knowledge that one has. Another highly emphasised issue acknowledged by the three participants was the active involvement required from the parents. The participants expressed that a lot of work and research has to be done by the parents, because, if they do not see to specific necessities, no else will.

The replies obtained from the participants acknowledge the importance of parents being actively involved throughout the service delivery procedure. The parents perceived their involvement as being highly important in communicating effectively the needs of the child to the professional/s.

### Theme 3: Funding Issues

This third theme was given substantial importance by the participants since it highly affects the outcome of the service delivery process and future AT application. Due to the expense involved in raising a child with disability in conjunction with the high costs of AT, the three parents agreed that funding support is necessary but limited. All the three parents opted to submit an application through both the Malta Community Chest Fund and KNPD. All the three participants maintained that when one puts the application through KNPD, the system delineates that first the applicant has to purchase the devices and subsequently apply for VAT refund.

### Theme 4: Barriers that hindered the service delivery process

*i.* <u>*Professionals' Attitudes*</u>

This barrier was highly emphasised by two of the participants, both of whom referred to the experience they had in the inclusive setting. The two mothers expressed how frustrating it was for them to work with professionals whose negative attitudes regarding disability proved to be a major hindrance.

*ii.* <u>*Lack of Resources*</u>

Two of the participants, shared the same views regarding the lack of resources available locally, and how this limited the efficacy of the process. The participants viewed lack of resources as having two aspects; both human and non-human resources. It was commonly argued that the lack of human resources creates an imbalance in the workload shared by the professionals currently in charge, because they have to speed up the process in order to keep up with the demand. Additionally, one subject commented about the lack of a formal assessment unit which makes the process irregular and requires extra effort from the parent. The lack of a specific assessment unit also leads to inappropriate assessments, in the sense that the case is not viewed holistically. The participant arrived to this conclusion due to the following:

## Conclusion

Respondents' perceptions regarding the service delivery process they experienced constituted the main results in this study. The themes that emerged subsequent to the analysis of the data were numerous since multiple questions were asked and subjective perceptions were gathered. This chapter has presented the gathered data in a logical manner, so as to outline the findings that emerged. In the following chapter, the findings will be related to the research questions put forward at the beginning of the study, and compared to the relevant literature.

## Discussion

This qualitative research study sought to clarify the service delivery processes of assistive computer technology in educational settings, which is currently being conducted in Malta. The fundamental questions to be answered were "What is the process, currently being followed locally, to enable children with physical disability obtain the required adaptations to computers used in educational facilities?" And "How do professional and non-professional individuals, who have been involved in the service delivery procedure, perceive the process?"

### The roles undertaken by organisations and the availability of their services –

This study indicated the lack of an official source which caters for the service delivery processes of Assistive Technology (AT) needs for children with disabilities. As stated by both the professionals and the parents, the recommendation and prescription for of assistive computer technology is being conducted by a limited number of professionals, each working individually. The ones mentioned in this study were the IT specialist, one physiotherapist at The Eden Foundation, and a learning support assistant along with an AAC specialist at San Miguel Special School.

All the professionals interviewed outlined their primary role in determining the AT needs for children with disabilities. Therefore, these professionals, guided by a different professional background, are individually conducting service delivery processes in each respective entity. This is undoubtedly resulting in a waste of resources, which could be otherwise utilised jointly, thus enabling a more efficient and effective outcome (Debono, 2006). Furthermore, this evidently indicates the lack of a multi-professional team involvement in the current service delivery processes. This is strongly opposed by Copley & Ziviani (2005), and multiple other literature on AT, in which team involvement is tremendously emphasised due to its fundamental influence on the service delivery process.

### The review of the service delivery process –

The reviews provided by San Miguel Special School and FITA indicate that they are following similar principles to conduct the procedure. These focus primarily on carrying out comprehensive assessments to identify the child's functional abilities and needs. Consistent with this, published research emphasises detailed assessments as a significant predictor for future acceptance and the use of the recommended device (Bain & Leger, 1997). The two assessments both include a trial and error procedure, through which the child is assessed using the various equipment owned by each organisation. Finally, the most appropriate device is strongly recommended by professionals, leaving the parents free to choose whichever device they consider suitable. This tallies with Cook and Hussey's (1995) published literature on assistive technology system designs to ensure a successful outcome.

Nevertheless, the two processes fail to address a number of key elements identified by Zabala et al. (2000), which enable the application of an effective service delivery process. Common to both organisations is the failure to promote active family involvement and the lack of a trans-disciplinary team approach during the assessment stage. Without doubt, this shortcoming highlights a serious gap in the current service delivery process, locally.

Furthermore, the service delivery process which is currently catering for the needs of children with physical disability is leading to misconceptions amongst parents, due to the fragmented manner in which information is being provided. This could be attributed to the fact that the process itself is complicated, time-consuming and does not follow a standard routine due to the lack of an official source.

**The assessment stage –**

Results from this study show that the assessment procedures carried out at FITA and San Miguel Special School have extensive overlap between them. The two assessment procedures indicate a sole issue which both foundations aim at determining; the child's physical limitations and skills. According to Bain & Leger (1997) the physical abilities influencing the child's performance is only one factor which needs to be addressed. Nevertheless, the professional conducting the assessment should not limit him/herself on solely verifying the motor abilities and needs of the child. The approaches conducted by both organisations fail to put into practice a systematic and comprehensive assessment which is guided by clear goals that are reached by team consensus, which is strongly suggested by Copley & Ziviani (2005).

The involvement of The Eden Foundation signifies that the assessments provided by FITA and San Miguel Special School are at times not being conducted with certain children, since the AT recommendations are being carried out at this non-governmental organisation. Despite the limitations in the current assessment procedures conducted by FITA and San Miguel Special School, the attempt at implementing the assessment stage is by and large considered more effective than completely omitting such a fundamental stage. These conclusions directly raise the issue of two linked factors which contribute towards The Eden Foundation's active involvement: the lack of a local official source catering for such needs; and, the foundation's early intervention with pre-school disabled children. The parents explained that how they were encouraged to seek additional treatment for their children from local NGOs, prior to being admitted to primary school.

**The trans-disciplinary team approach –**
The study then focused on exploring the application of a trans-disciplinary team approach, which is considered as a fundamental principle in any AT service delivery process (Cook & Hussey, 1995; Bain & Leger, 1997; Lahm & Sizemore, 2002; Copley & Ziviani, 2005). Results clearly show that all the processes discussed in this study, failed to adopt a team-based approach to determine the assistive computer technology needs for each child. On the contrary, the procedures outlined by both the parents and the professionals strongly indicate an individualistic approach which is being practiced in all the facilities involved in this study. These findings do not tally with any of the research literature which has been reviewed. Such literature strongly highlights the involvement of individuals representing various disciplines who are able to work as a team and communicate effectively (Bain & Ledger, 1997; Zabala et al, 2000; Copley & Ziviani, 2005, Parette, Huer & Scherer, 2004).

The study further sheds light on the lack of knowledge amongst the majority of the participants about the implications of trans-disciplinary teaming. These findings were also documented in a study conducted locally by Gatt (2007), in which stakeholders acknowledged their lack of knowledge and failure to implement team-based approaches.

Adding to the failure of putting this approach into practice, results reveal multiple misconceptions regarding the manner in which trans-disciplinary teaming should be utilised. One of the most striking misconceptions amongst 50% of the professionals and all the parents was the belief that trans-disciplinary teaming was being employed once the organisations providing financial assistance were asked to step in and evaluate accordingly. These results strongly oppose the studies conducted by Shuster (1993), who comments on the importance of having team members attending all the assessment meetings to collectively pool ideas and jointly decide upon the most appropriate device.

**Family Involvement –**
Although AT literature (Lahm & Sizemore, 2002; Copley & Ziviani, 2005; Knox & Menzies, 2005; and Parette, Huer & Scherer, 2004) considers the involvement of the family members during service delivery processes as highly important, the issue was scarcely discussed by the professionals. The professionals' common judgement regarding the family's involvement focused solely on the parents' role in making the final choices regarding the device purchased. Knox & Menzies (2005) similarly determined that the family members should be the ones making free choices and deciding upon all aspects regarding their child's health care. In a study regarding the role of the family members during AT service delivery processes, Parette & Hourcade (1997) suggested an opposing viewpoint

to these professionals' attitudes: the study encourages the view that parents need to acquire a sense of control over the given services, thus ensuring a greater level of contribution and active participation. A collaborative family-centred model is also recommended by Copley & Ziviani (2005), since it enables mutual collaboration, expression of personal viewpoints, and feelings of worthiness.

Contrary to the professionals' perceptions, the parents emphasized the significance of their contribution in expressing the needs of their children and ensuring that the most favorable decisions are put into practice. The parents said that their involvement should have extended to a discussion about aspects regarding their child, their way of living and their cultural beliefs, outside the school setting, since these would have influenced the outcomes of the chosen device. This is similar to the study conducted by Parette, Huer & Scherer (2004), which states that with the increasing number of students with disability from various cultural backgrounds, the service delivery process must shift its focus on strategies which promote decision-making processes sensitive to cultural factors.

**Funding sources and issues –**
This subject was the primary concern highlighted by all the participants, especially the parents. In fact, the reviews regarding the parents' own experiences of the service delivery process centred mostly on the stage of acquiring financial support. As discussed by Zabala et al. (2000), Lahm & Sizemore (2002), and Copley & Ziviani (2004), this attitude is to be expected since funding is the major barrier for individuals trying to access assistive technology equipment.

It was commonly agreed by all the participants that financial assistance is rendered through two funding sources: the Malta Community Chest Fund and the National Commission Persons with Disability (KNPD), both being agencies primarily developed for the provision of such services. These findings tallied with Cook & Hussey (1995), who stated that since most individuals do not have the necessary financial resources to purchase the required devices, funding through third-party sources is essential. Although the study further draws attention to the ongoing challenge in acquiring financial assistance, this had not been a burden for any of the three parents.

**Barriers that hinder the service delivery process –**
Participants in this study all expressed their perceptions regarding barriers that need to be overcome to improve the current service delivery process which is provided locally. Attitudinal barriers, the lack of awareness and the lack of resources were the 3 areas given most importance by participants.

All the participants in this study firmly agreed that the professionals' attitudes (namely teachers), and perceptions in local mainstream schools, are the major hindrance influencing the service delivery processes, as well as the use of AT devices in educational settings.

These results tally with much of the literature dealing with AT for students with disabilities (McGregor & Pachuski, 1996; Parette & Hourcade, 1997; and Copley & Ziviani, 2006; Gatt, 2007), in which it is suggested that teachers and other educational professionals, are the least likely individuals to take active roles in such services. The reluctance of professionals working in educational settings might be traced to the lack of suitable training provided for the school personnel. This issue is in line with the study conducted by Copley & Ziviani (2006), where many teachers claimed that they resisted or rejected the use of assistive computer technology devices due to inadequate training and the feeling of incompetence in operating the devices.

The participants also put an emphasis on the lack of financial resources which are currently being provided in the field of AT provision. The high costs of AT devices and the lack of funds available to meet these costs were reported by every participant. These viewpoints were similar to those documented in Gelderblom & P. de Witte (2002), Debono (2006) and Gatt (2007). From the professionals' point of view, this issue was further discussed in terms of the lack of equipment available to assess the child's functioning on various assistive computer technologies, thus greatly restricting the quality of the assessments.

## Conclusion

This study shows that while various organisations attempt to conduct an effective and efficient service delivery process, multiple factors are restricting this procedure. The findings of this study clearly show that professionals who are currently providing the services lack knowledge on three primary fundamental issues, which highly influence AT provision, namely, the involvement of a team approach; adopting a family centred approach; and, conducting a comprehensive assessment. It is for this reason that this study suggests the establishment of a specialised, official centre in which Occupational Therapists assume a major role in determining AT requirements for school children with a disability.

The founding principles of OT enable the practicing therapist to address the current loopholes present in the local AT services. Occupational Therapy respects and acknowledges the importance of intervention from various professional backgrounds, thus ascertaining that the knowledge and experience of each professional attends to the complex array of factors which influence decisions regarding AT. Occupational Therapy further recognises the importance of caring for the needs of the family since active family involvement is necessary in ensuring cooperation and AT use. Finally, the occupational therapist is uniquely capable of identifying abilities and impairments in all performance components which are hindering the child's development, and to address these in conjunction with his/her personal and environmental contexts. The latter makes the therapist competent in conducting a systematic and comprehensive assessment, since this is a crucial stage in AT service delivery processes. This would be a sound basis to empower disabled children to be fully integrated within mainstream activities since:

> *Computer application can serve as an equalizer for a child with disabilities so that he or she can function in the same settings and in similar activities engaged in by typical young children... Technology used thoughtfully and creatively rather than as a teaching machine can engender and support educational environments that will empower children to flourish in the 21 st century.*
> (Judge, 2001).

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**Book Reviews** by Chia Swee Hong,
Lecturer in Occupational Therapy, University of East Anglia

**Perspectives on rehabilitation and dementia.**
**(Ed) Mary Marshall**
**Jessica Kingsley**
**London.**
**2005.**

Although there are a number of definitions of rehabilitation, the common denominator is the adoption of a positive and realistic approach to the care and management of people with disabilities. They can function better with appropriate support. Although people with dementia are unlikely to be able to return to their normal level of function before the onset of the condition, they can maintain their ability with appropriate course of rehabilitation.

This book challenges practitioners to use concepts of rehabilitation with people who have dementia to help them maintain their independence. It consists of seven parts: part 1 - perspectives on rehabilitation and dementia, part 2 - perspectives of people with dementia and their carers, part 3 - perspectives from a range of professions e.g. occupational therapy, part 4 - settings e.g. rehabilitation in acute medical wards, part 5 - specialised interventions e.g. the use of assistive technology, part 6 - specific difficulties such as visual impairment and dementia and part 7 – reflection of current practice and research findings.

There are numerous thought provoking questions which prevail in the book such as why rehabilitation for people with dementia and why do people with dementia become disabled? Each chapter is well written and contains relevant information and is supported with case scenarios and or references. Readers of this journal will find Chapters 5 and 13 of great interest: Chapter 5 has an extensive review of the evidence to support rehabilitation with people who have dementia. The review confirms that people with dementia can benefit from rehabilitation. The author of this chapter notes the paucity of research studies and urges practitioners to ensure that people with dementia are included in future research undertakings. Chapter 13 offers an account of the role of OT with people who have dementia. This is a useful chapter which justifies the role of OT in dementia care and presents briefly some of the assessment and therapeutic strategies used in practice. Readers of this journal will also find it useful to read a publication by J Pool: The Pool Activity Level (PAL) Instrument for occupational profiling – a practical resource for carers of people with cognitive impairment (Jessica Kingsley, 2008). A further discussion of themes such as spirituality will be useful in a future edition.

This is a well edited book with contributors ranging from academics, carers, clients and practitioners working with people who have dementia. It will be of immense value in helping practitioners to consider the potential role of rehabilitation in maintaining/improving the abilities of people with dementia.

**Ethical issues in dementia care**
**Julian C Hughes and Clive Baldwin**
**Jessica Kingsley**
**London**
**2006**

There are always difficult questions and decisions experienced and made by practitioners with people who have dementia on a regular basis. Any decision is usually informed by value judgements on what it is felt to be the right or wrong course of action.

According to the authors, moral theories give practitioners means of understanding about what might constitute a good thing and what might constitute a bad one. They can offer a structure for ethical decisions which practitioners have to make regularly. The application of moral theories can be a challenge in "the busy world of dementia care" (Pg16). The authors suggest that one method of overcoming the problem of choosing the right moral theory is "principlism" which is based on the following principles:

- Enabling people to decide what they want to happen or be done to them
- Doing good to them
- Avoiding harm to them
- Treating them fairly and equally

Having introduced principlism, the authors contend that "moral theories and principles do not provide neat and tidy answers. Actually, they can sometimes make matters more complicated" (Pg 24). They suggest the use of an informed conscience which is acquired through education and upbringing. Subsequent chapters consider thoroughly the following relevant themes:

- Consent and capacity to treatment
- Emphatic relationships
- Good quality of life and end of life
- Patterns of decision making process in practice

The chapters are clearly and sensitively written with effective use of case scenarios and research studies to inform the argument presented by the authors. A little more consideration to the needs of people with dementia and their carers from different religious and cultural backgrounds will be useful in a future edition.

This book will be of great value to all practitioners who are confronted with ethically related questions on a regular basis.

# Annual General Report- 2008-09 Financial Report

| | Credit | Debit |
|---|---|---|
| Income promotional material | €289.72c | |
| Income membership fees | €412.63c | |
| Expenditure refreshments | | €49.05c |
| Income assertiveness course fee | €855.00c | |
| Expenditure assertiveness course fee | | €840.00c |
| Income profit from fundraising From BBQ & OT National Day | €91.50c | |
| Expenditure for stamps and stationary Including certificate papers etc…* | | €253.40 |
| Income donations | €6.86c | |
| Expenditure painting for Dr. Micallef | | €35.00c |
| Expenditure for WFOT membership | | €43.50c |
| Expenditure for COTEC membership | | €50.00c |
| Expenditure for website updates | | €30.96c |
| Expenditure for badges | | €107.38c |
| Expenditure for key chains | | €324.50c |
| Expenditure for leaflet translation (Amputee) | | €100.00c |
| Income bank interest | €64.75c | |
| Income for CPD certificates (non-members) | €28.00c | |
| | **€1748.46c** | **€1833.79c** |

* Stamps, Christmas cards, photocopies for certificates, certificate papers, photocopies for journal and binding

<u>Bank</u>

| | | |
|---|---|---|
| **Savings** | **€8307.93c** | |
| **Of which belong to MAOT** | | **€3,719.23** |
| **Of which belong to CDAU** | | **€4,588.70** |
| **Current** | **€36c** | |
| **Petty Cash** | **€86.98c** | |

**Roberta Sultana – MAOT Treasurer**