

The current situation of disabled persons with challenging behaviour in Malta

EXECUTIVE SUMMARY 2012

ESF 3.105

Promoting the social inclusion of disabled
persons with challenging behaviour



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This research is a detailed study of the quality of life of disabled persons with challenging behaviour. Disabled persons who have challenging behaviour are among those who are most at risk of exclusion from society, education and training, and the labour market.

Challenging behaviour is an all encompassing term which refers to a number of behaviours which can prove detrimental to disabled person themselves as well as others around them. Challenging behaviour can be defined as:

‘culturally abnormal behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.’¹

Challenging behaviour may be an attempt to gain control of a confusing world. In severe cases, challenging behaviour can result in serious or fatal injury, such as brain damage as a result of head banging. However in many cases, the behaviour is mild or moderate, but can still cause a lot of distress and disruption to all those affected. The population of disabled persons with challenging behaviour in Malta receiving a service is estimated to be over 1000.

This research was conducted as part of the project entitled ‘Promoting the social inclusion of disabled persons with challenging behaviour (ESF3.105) which is co-financed by the European Social Fund (ESF), Operational Programme II – Cohesion Policy (2007 – 2013). This project intends to provide training for staff working with disabled persons who have challenging behaviour. After the end of the training, the staff can

train other staff within their respective organisations. The results of this research are intended to inform the terms of reference of the tender of the mentioned training.

The research, carried out through face-to-face interviews between May and June 2012, is based on the following two population samples:

- 100 disabled persons with challenging behaviour or their primary care givers. Two disabled persons actively participated in the face-to-face interview. In all other interviews, the disabled person was represented by his or her primary care giver (his or her parent or relative or a care worker).
- 100 persons working with disabled persons with challenging behaviour.

It is pertinent to underline that a number of parents approached to participate in the survey either refused or initially accepted but subsequently refused to participate when they were informed that the research focused on disabled persons with challenging behaviour. In instances the parent specifically stated that he or she do not consider the son or daughter to have a ‘challenging behaviour’. Of the 119 parents approached, the final 100 person sample population is constituted as shown in Figure 1.

No difficulties were experienced in bringing together the sample population of staff members working with disabled persons with challenging behaviour. The staff members identified were selected on the basis of an invitation issued by the researcher to appropriate organisations identified by KNPD. The 100 staff member sample population is constituted as shown in Figure 2.

1 E. Emerson's (1995) *Challenging behaviour: analysis and intervention with people with learning difficulties* (Cambridge University Press

DISABLED PERSONS WITH CHALLENGING BEHAVIOUR OR THEIR PRIMARY CARE GIVERS

Figure 3 presents the age and gender profile of the sample population (n=100). As can be seen from Figure 3, 10 of the disabled persons in the age group between 40 to 70 years and over are female – or 66.6% of the disabled persons within this age group. On the other hand, 55 of the 85 disabled persons in the age group between 0 years to 39 years of age are male – or 64.7% of the disabled persons in this age group.

The locality with the highest number of respondents is the Southern Harbour Region (29%).

Figure 1: Disabled Persons Sample Representation

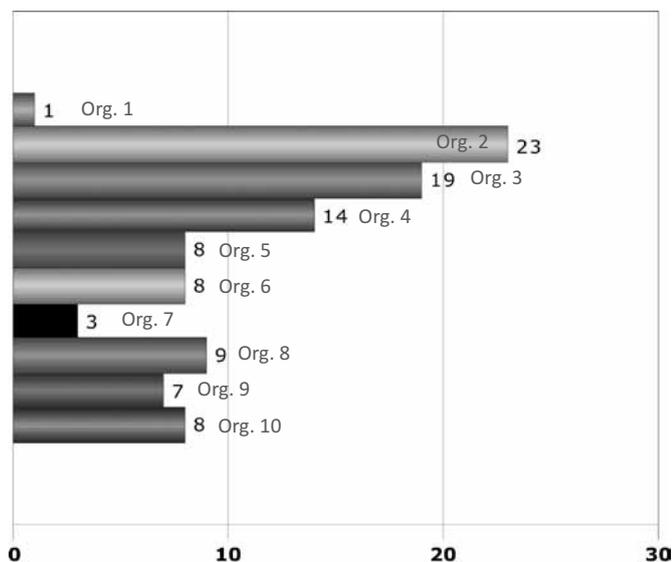
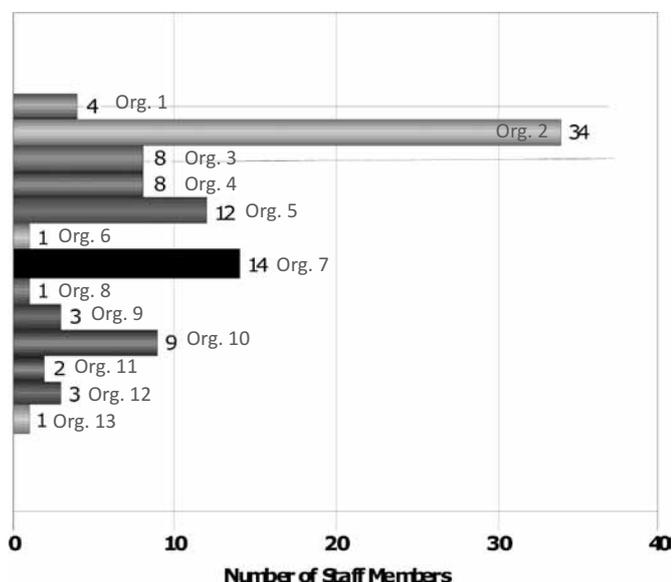


Figure 2: Staff Members Sample Representation



This is followed by the Northern Harbour Region and the Northern Region respectively – both with an 18% representation of the total population. Figure 4 presents the disabled persons and the localities – with the localities classified in districts according to the Malta Geographical Code².

The total number of disabled persons who reside in Gozo is 13. As can be seen from Figure 5 8 disabled persons, or 61.5% of the Gozo sample (n=13) or 8% of the total sample (n=100), are female. Of the 6 disabled persons who are in the age group between 30 years to 70 years and over, 5 are female – 38.46% of the Gozo sample or 5% of the total sample.

Figure 6 shows that 74% of the disabled persons live at home with their parents (or other family members) whilst 26% of the disabled persons live in a residence or in an institution or in a supported environment. The majority of disabled persons in the 0 to 29 age group live with their parents, whilst the number of disabled persons who live in a residence or institution or supported environment increases as a disabled person with challenging behaviour becomes older.

The relationship between the disabled person and the primary care giver is one where 70 disabled persons live with their parents, 4 with their relatives

2 Localities:

Southern Harbour	Żabbar, Xgħajra, Valletta, Tarxien, Santa Luċija, Paola, Marsa, Luqa, Kalkara, Senglea, Floriana, Fgura, Cospicua, Vittoriosa.
Northern Harbour	Ta' Xbiex, Swieqi, Sliema, Santa Venera, San Ġwann, St. Julians, Qormi, Pieta', Pembroke, Msida, Hamrun, Gżira, Birkirkara.
South Eastern	Żurrieq, Żejtun, Safi, Qrendi, Mqabba, Marsaxlokk, Marsascala, Kirkop, Gudja, Ghaxaq, Birżebbuġia.
Western	Żebbuġ, Siggiewi, Rabat, Mtarfa, Mdina, Lija, Iklin, Dingli, Balzan, Attard.
Northern	St. Paul's Bay, Naxxar, Mosta, Mġarr, Mellieħa, Ghargħur.
Gozo and Comino	Rabat, Fontana, Ghajnsielem and Comino, Għarb, Għasri, Kerċem, Munxar, Nadur, Qala, San Lawrenz, Sannat, Xagħra, Xewkija, Żebbuġ.

Figure 3: Profile of Disabled Persons by Age and Gender

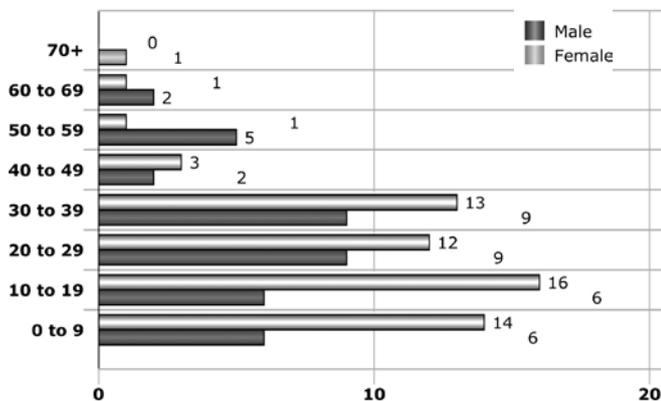


Figure 4: Profile of Disabled Persons by Locality from Where They Come From

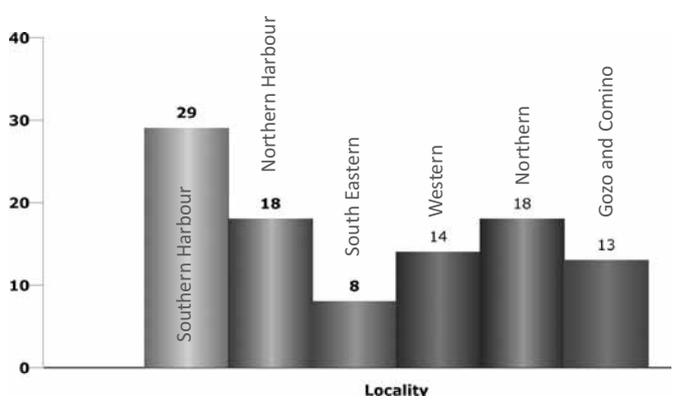
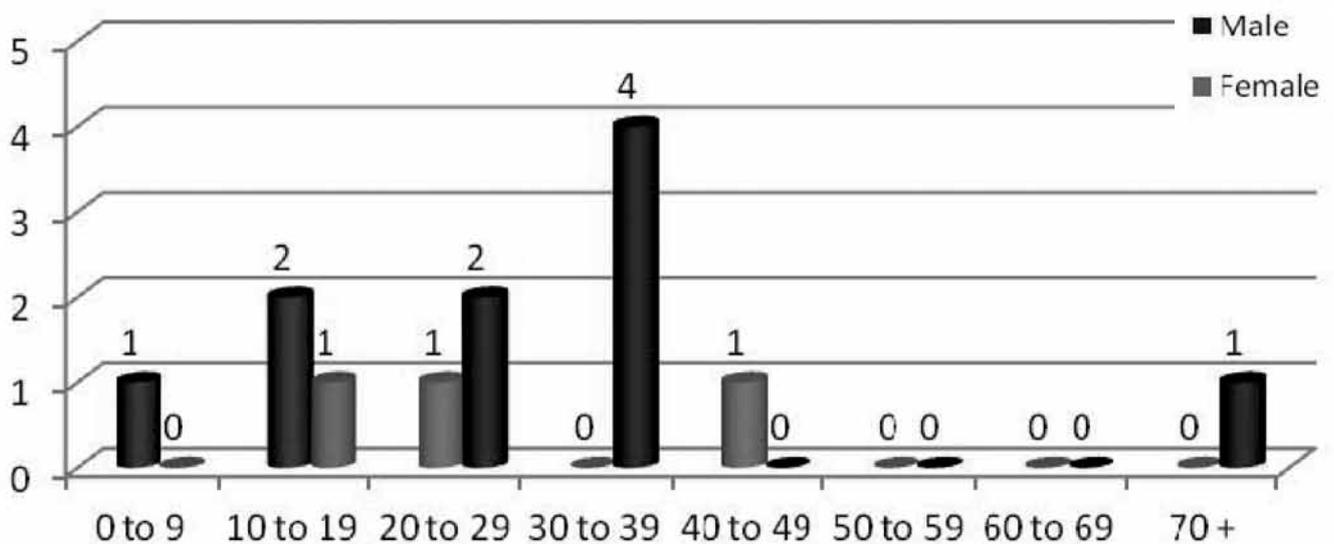


Figure 5: Gender of Disabled Persons who Live in Gozo



and 26 are supported by staff members working in community-based homes, or institutional households.

The number of females who live with their parents or other family members and those who live in a community-based home, or institutional household are 25 and 15 respectively.

Of the 13 disabled persons who reside in Gozo, 12 live with their parents, whilst 1 lives in a supported environment. In all instances the primary care giver is the parent.

Figure 7 shows the total number of impairments and/or conditions experienced by disabled persons. The most prevalent condition is autism (42), followed by 'other mental illness' (16) and intellectual impairment (12).

It is to be noted that 73 of the disabled persons have one impairment and / or condition; 22 have two impairments and / or conditions; and 5 have 3 impairments and / or conditions.

It emerges that 8 disabled persons are reported to have no manifestation of challenging behaviour

Figure 6: Age of Disabled Persons and Place of Residence

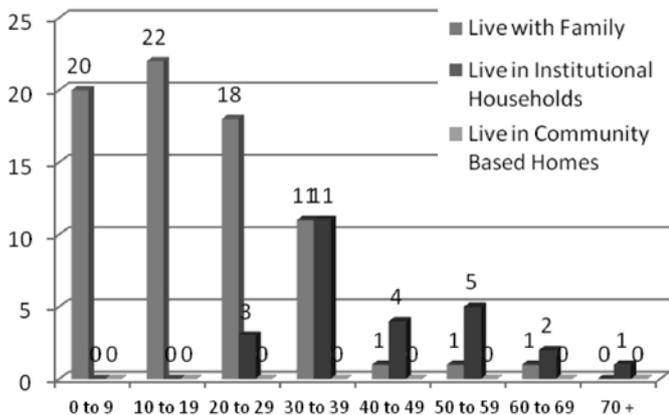


Figure 7: Total Number of Impairments and/or Conditions of Disabled Persons

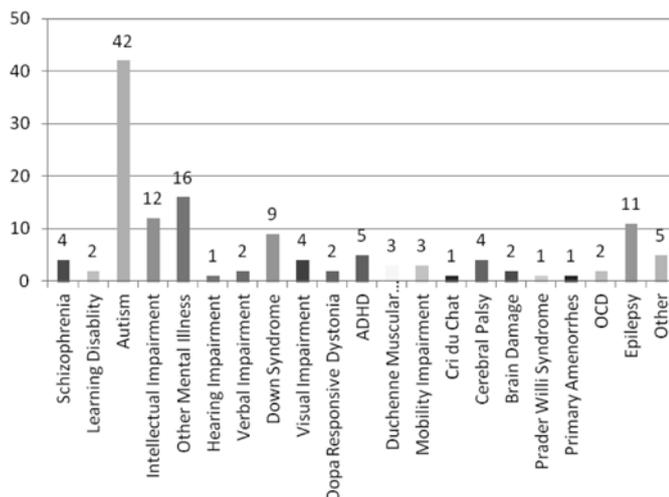


Figure 8: Number of Impairments and/or Conditions per Disabled Person

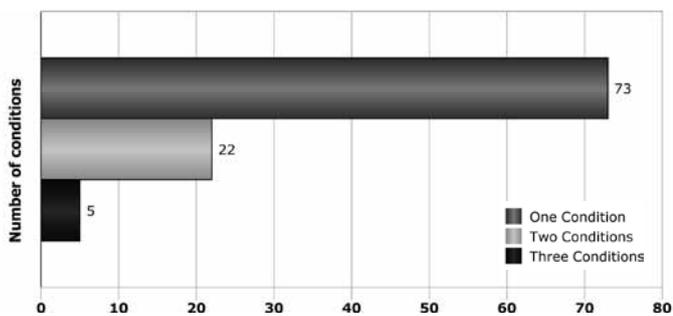


Figure 9: Total Number of Manifestations Identified

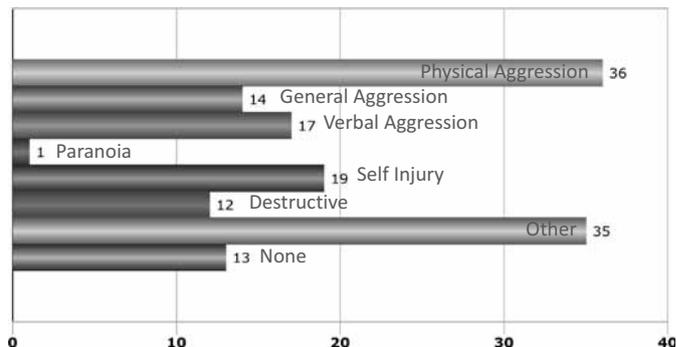


Figure 10: Number of Manifestations per Disabled Person

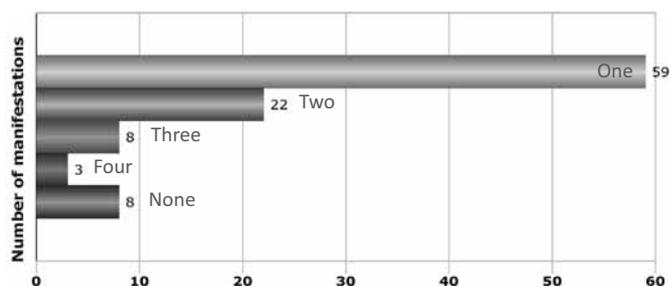
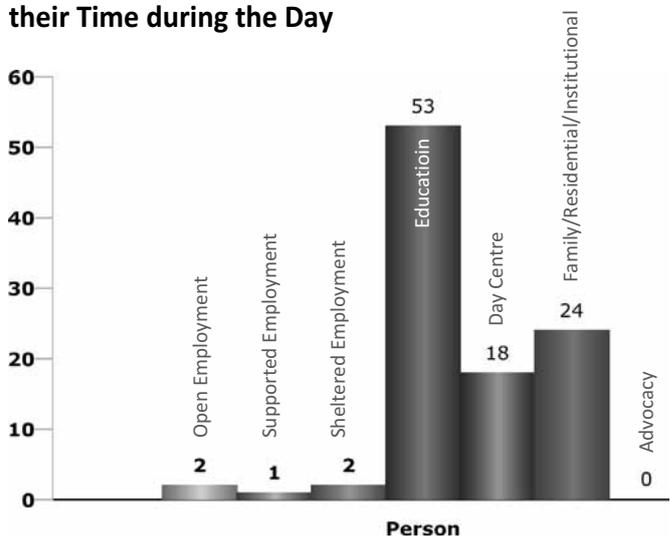


Figure 11: How Disabled Persons Spend their Time during the Day



at time the survey was carried out. The disabled persons who experience one or more manifestations number 92. The total number of manifestations that disabled persons experience is 134. The most prevalent manifestation is aggression – with physical aggression standing at 36, verbal aggression at 17 and general aggression – which is defined to mean mild or occasional manifestations of aggression – at 14.

Fifty-nine of the disabled persons surveyed experience one manifestation; whilst 22 experience two manifestations.

Figure 11 shows where disabled persons with challenging behaviour spend most of his or her time during the day.

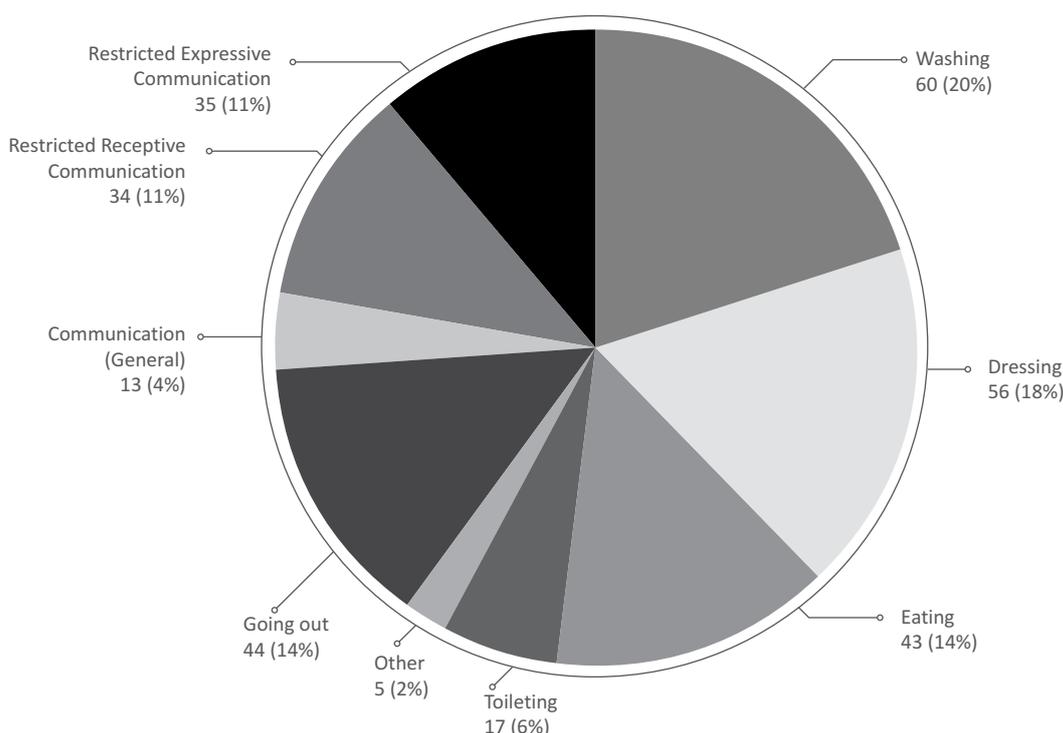
Of note is that of the 100 disabled persons sampled none attend any form of advocacy programmes. Forty-two of the disabled persons interviewed carry out a social and recreational activity – which covers a broad spectrum of activities.

The survey shows that 24 of the disabled persons interviewed require no assistance to carry out their daily activity needs – although a number state that they require different degrees of guidance or

supervision. Nine (37.5%) of these disabled persons reside in Gozo. The remaining 76 disabled persons require a total of 307 types of daily assistance – which, on average, means a disabled person requires four different types of assistance during the day. The types of different daily activity needs for which support is required by the sample population (n=74) are shown in Figure 12. Fifty two percent of the daily need requirements result from three basic functions: washing; dressing and eating. Assistance in communication constitutes 26% of the daily activity needs for which support is required; whilst going out constitutes 14% of the daily activity needs. ‘Others’ include activities such as money management.

Seventy-one primary care givers answered the open ended question on improvements and / or concerns. Of the 29 respondents who did not answer 8 are parents or relatives, and 2 are disabled persons who directly participated in the interview. The remaining 19 non-respondents are staff members responsible for disabled persons who reside in a community-based home or institutional household. Of those who responded, most presented more than one recommendation and / or concern.

Figure 12: Types of Daily Activity Needs Required



STAFF WHO WORK WITH DISABLED PERSONS WITH CHALLENGING BEHAVIOUR

The staff members all describe situations and events that are unique in many ways, whilst also sharing similar beliefs, experiences, and feelings concerning disabled persons' social and emotional development. Overall, the professionals in this survey reiterated how they make an effort to treat all disabled people fairly, and they encourage confidence in their disabled persons by providing an environment that is safe, loving, and nurturing. Eighty eight percent of the sample interviewed for this research is female.

A similar ratio is observed for staff members in Gozo.

When working with disabled persons with challenging behaviour, 83% of the staff members interviewed believe that adopting a calm approach with the disabled person is the approach that can help the most. An overview of their opinions

Figure 13: Gender of Staff Members

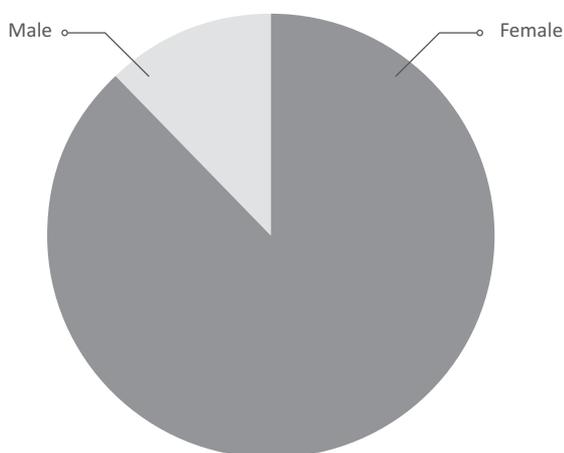
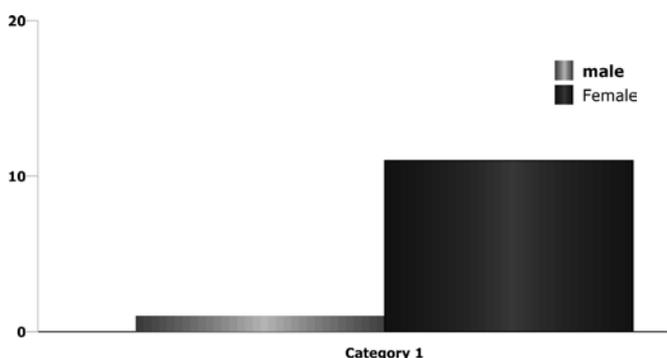


Figure 14: Gender of Carers in Gozo



with regard to the care of disabled persons with challenging behaviour is shown in Figure 15.

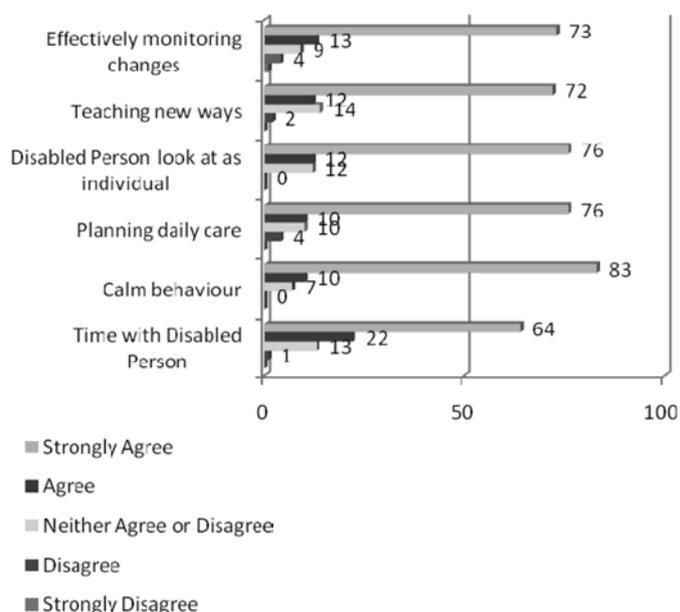
The staff members, in the main, are in agreement that by effectively monitoring changes (73%), teaching disabled persons new ways to do things (72%), looking at disabled persons as individuals (76%), planning the daily care of disabled persons (76%), taking on a calm disposition towards disabled persons (83%) and spending time with the disabled persons (64%) would be beneficial for disabled persons with challenging behaviour.

The staff members in this research also cite the disabled persons' parents' values and disciplinary styles of disabled persons' parents, as important influences on their approaches and responses to disabled people's behaviour.

The staff members in the main, are confident of the manner that they are dealing with disabled persons with challenging behaviour, with only 9 females and 1 male professional remarking that they felt a lack of 'some' confidence.

There are several pathways that staff members take on their route to working with disabled persons with challenging behaviour and Figure 17 gives an overview of the qualifications that the professionals achieved.

Figure 15: Approach to Disabled Person by Professionals



Staff members who do not possess any qualifications refer to experience within the sector to make up for that lack of professional qualifications. It is also noted that the range of these professional qualifications are varied, e.g. teaching degrees and psychology degrees. Following their initial qualification, 76% of the professionals undertook specialised training in the area of challenging behaviour related to their job.

CONCLUSION

This survey has sought to present an understanding of disabled persons with challenging behaviour, and through such an understanding provide information that will allow for appropriate policy design.

A number of observations that are to be taken into consideration in policy design with regards to disabled persons with challenging behaviour are noted. First, there is a concern, if not a fear, amongst parents to have their son or daughter labelled as a person with challenging behaviour. The difficulty in reaching the appropriate 100 person sample and the statements expressed by persons in this regard indicate that if a disabled person is “labelled” to have challenging behaviour, then that person is “stigmatised” and potentially perceived to be an illiterate person.

One of the statements presented by parents is the need to educate society generally and entities specifically (such as schools) with regard to challenging behaviour so that such disabled persons are understood better and allowed to integrate further. The statement was made a number of times on the need for the parents themselves to be trained on how best to manage a son or daughter with challenging behaviour as well as for parents to be afforded the appropriate support, such as respite, as managing challenging behaviour can be “exhausting” and “shattering”. It is to be noted, that this is an observation that is also stated by staff members.

Second, disabled persons who reside in Gozo are all cared for by their family, and with the exception of one disabled person who resides in a supported environment, all live at home. It is to be noted that 3 (23.1%) of the parents of disabled persons who

Figure 16: Confidence Felt when Looking After Disabled Persons by Gender of Staff Members

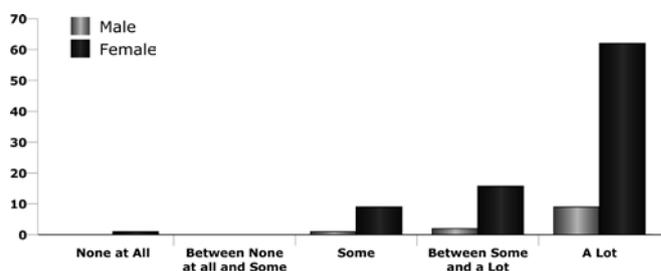
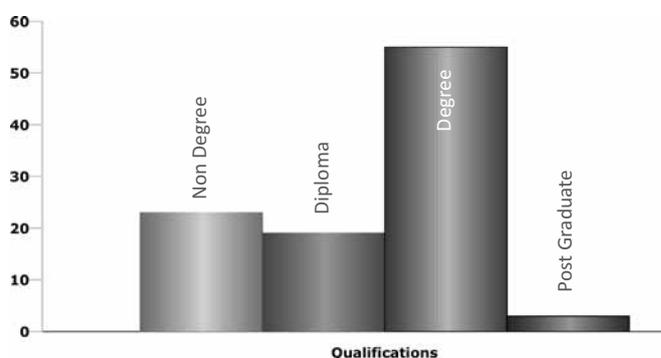


Figure 17: Training Followed by Staff Members

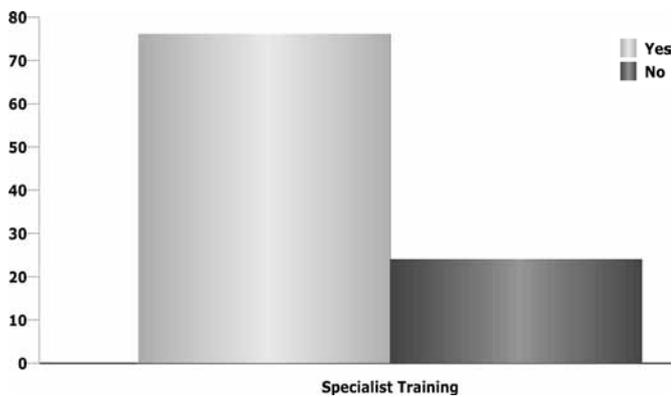


reside in Gozo remark that there are no supporting facilities in Gozo to which parents of disabled persons can turn to.

Third, the absence of supporting frameworks that assist parents as well as disabled persons with regard to social and recreational activities as well as ongoing extracurricular activities requires particular attention. The statement was made, repeatedly, that the fact that the disabled son or daughter is restricted to his or her home or place of residence for long periods of times increases the level of frustration and, potentially, accentuates challenging behaviour’

With regard to the staff members the following observations are noted. First of all, the carers made a recommendation which merits serious consideration, that is, that there is a need for the development of training facilities for professionals, which should target specialised topics on challenging behaviour. Expressions used in the interviews, such as: “it was very frustrating”, or “I didn’t know what to do,” indicate that the participants would benefit from in-service

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Figure 18: Specialist Training Conducted on the Job



training, or professional development, in behaviour management and also on specific needs of each type of impairment or condition.

Second, it was proposed that there should be a pooling of existing resources so that hospital staff members gain more access to the disabled person at home. Access to services is constantly a lament by parents – whether this relates to the limited state services available; the need to complement this by

expensive services or support from NGOs or private sessions with therapists; or the time required to take the son or daughter to and from therapy, particularly if the parent does not have a private car. The staff members felt that they have such a varied cohort of disabled persons that their expertise is often stretched and consequently they cannot reach out enough to disabled persons and parents as well as it should.

Third, it was proposed that there is a need for a training programme that provides training in the practice of reflection. Staff members that come through the route of teacher training or psychology programmes should be instructed on reflective teaching training in order for them to be able to continuously develop their work practices with disabled persons with a challenging behaviour. It is underlined that this could be linked up to a support structure within organisations. The staff of one specific school reported that there is a real need for support structures for professionals working within the disability sector, so that they are able to share their experiences and learn from each other.



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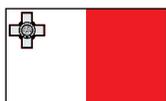
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Operational Programme II – Cohesion Policy 2007–2013
Empowering People for More Jobs and a Better Quality of Life
Project part-financed by the European Union
European Social Fund (ESF)

Co-financing rate: 85% EU Funds; 15% National Funds

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