'The Current Situation of Disabled Persons with Challenging Behaviour in Malta: Research and Dissemination'

Date: 6th August 2012
Executive Summary

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.’

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:

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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.

Figure 01: Disabled Persons Sample Representation

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.
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 are male – or 64.7% of the disabled persons in this age group.

Figure 3: Profile of Disabled Persons by Age and Gender

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

² Localities

<table>
<thead>
<tr>
<th>Southern Harbour</th>
<th>Zabbar, Xghajra, Valletta, Tarxien, Santa Luċija, Paola, Marsa, Luqa, Kalkara, Senglea, Floriana, Figura, Cospicua, Vittoriosa.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Harbour</td>
<td>Ta' Xbiex, Svieqi, Sliema, Santa Venera, San Ġwann, St.Julians, Qormi, Pieta', Pembroke, Msida, Hamrun, Gżira, Birkirkara.</td>
</tr>
<tr>
<td>South Eastern</td>
<td>Żurrieq, Żejtun, Safi, Qrendi, Mgħabba, Marsaxlokk, Marsascala, Kirkop, Gudja, Ghaxaq, Birżebbuġia.</td>
</tr>
<tr>
<td>Western</td>
<td>- Żebbuġ, Siġġiewi, Rabat, Mtarfa, Mdina, Lija, Iklin, Dingli, Balzan, Attard.</td>
</tr>
<tr>
<td>Northern</td>
<td>St. Paul's Bay, Naxxar, Mosta, Mgarr, Mellieha, Gharbghur.</td>
</tr>
<tr>
<td>Gozo and Comino</td>
<td>Rabat, Fontana, Ghajnsielem and Comino, Gharb, Ghasri, Kerċem, Munxar, Nadur, Qala, San Lawrence, Sannat, Xagħra, Xewkija, Żebbuġ.</td>
</tr>
</tbody>
</table>
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 and 26 are supported by staff members working in community-based homes, or institutional households.

**Figure 6: Age of Disabled Persons and Place of Residence**

The number of females who live with their parents or other family members and those who live in a community-based home, or residential 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).
Figure 7: Total Number of Impairments and/or Conditions of Disabled Persons

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.

Figure 8: Number of Impairments and/or Conditions per Disabled Person
It emerges that 8 disabled persons are reported to have no manifestation of challenging behaviour 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.

**Figure 9: Total Number of Manifestations Identified**

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

**Figure 10: Number of Manifestations per Disabled Person**
Figure 11 shows where disabled persons with challenging behaviour spend most of their time during the day.

**Figure 11:** How Disabled Persons Spend their 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) is shown in the 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 respond, most presented more than one recommendation and/or concern.

**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 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.

Figure 13: Gender of Staff Members
Figure 14: Gender of Staff Members in Gozo

Figure 15: Approach to Disabled Person by Staff members
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 staff member remarking that they felt a lack of ‘some’ confidence.

**Figure 16:** Confidence felt when Looking after Disabled Persons by Gender of Staff Members

![Bar Chart](image)

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 staff members achieved.

**Figure 17:** Training Followed by Staff Members

![Bar Chart](image)
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 staff members undertook specialised training in the area of challenging behaviour related to their job.

Figure 18: Specialist Training Conducted on the 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 is “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 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 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 is 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 staff members made a recommendation which merits serious consideration, that is, that there is a need for the development of training facilities for staff members, 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 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 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 staff members working within the disability sector, so that they are able to share their experiences and learn from each other.
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01. Introduction

01.1 Terms of Reference

The Kummissjoni Nazzjonali Persuni b’Diżabilità (KNPD), under the ambit of a European Social Fund (ESF) Project (ESF 3.105 – Promoting the Social Inclusion of Disabled Persons with Challenging Behaviour) embarked on a project directed to:

**Carry out research on the current situation of disabled people with challenging behaviour in Malta and Gozo.**

**Provide training for organisations providing services for disabled people with challenging behaviour in Malta and Gozo.**

**Make policy recommendations vis-a-vis provision for disabled people with challenging behaviour in Malta and Gozo.**

KNPD issued a call for applications for the first part of the project with the overall objectives to:

**Understand the demographics of disabled persons with challenging behaviour, the services they are currently receiving and their support needs.**

**Study the prevalence of challenging behaviour in disabled persons, their involvement in mainstream services, and their support needs.**

**Identify training needs.**

**Inform policy recommendations.**
More specifically, the research study is to determine:

**The number of disabled people who are considered to have challenging behaviour.**

**The number living in institutional households.**

**The number living in community based homes.**

**The number in each group who spend most of their time in their place of residence.**

**The number who make use of services outside the place of residence which specifically cater for disabled persons.**

**What these services are and how many make use of each service.**

**The factors identified by those living and working closely with disabled people with challenging behaviour as making it possible for these people to make use of the different services.**

**The factors identified by those living and working closely with disabled people with challenging behaviour as creating obstacles for these people to make use of different services.**

**The proposed solutions put forward by those living and working closely with disabled people with challenging behaviour.**

**Issues that are specific to disabled men and women.**

**Issues that are of specific relevance to disabled persons with challenging behaviour who live in Gozo.**
DPCB Joint Venture (JV) (hereafter referred to as the researcher), constituted of DSG Consulting Ltd and International Vocational College Malta, were awarded the tender to carry out this research assignment. The specific terms of reference set for the research are to:

**Draw up the questionnaires, interview schedules and other research tools as appropriate to be submitted as part of the interim report.**

**Collection of data from the implementation of questionnaires through face to face interviews and other research tools with those living and working closely with disabled persons with challenging behaviour.**

**Implementation of questionnaires through face-to-face interviews and other research tools with approximately 100 disabled persons with challenging behaviour or primary their care givers.**

**Implementation of questionnaires through face-to-face interviews and other research tools with approximately 100 persons working with persons with challenging behaviour.**

**Brief review of relevant local and foreign literature.**

**Attendance of consultation meetings with KNPD and project partners.**

**Coordination with KNPD for it to provide induction disability equality training for researchers involved.**

**Presentation of final report and of results in a half day seminar.**
The research work initiated on 26\textsuperscript{th} March 2012. The target completion date for the presentation of the report was 1\textsuperscript{st} July 2012. Given the difficulties encountered in bringing together the 100 person target sample of disabled persons with challenging behaviour (hereafter also referred to as disabled persons) or their primary care givers the timeframe for the completion of the project was, following discussions held with KNPD during Project Review Board meetings, extended to 1\textsuperscript{st} August 2012.
02. Review of Literature

02.1 Defining Challenging Behaviour

Challenging behaviour amongst people with intellectual and other disabilities can significantly interfere with their quality of life, the quality of life of other service users and those who live with and care for them.

Those with intellectual and other disabilities and challenging behaviour may be excluded from schools or day services. They may be prescribed high levels of medication to control their behaviour. Their families may reach ‘breaking point’ and request alternative residential provision. Many people with intellectual and other disabilities and challenging behaviour have additional health needs that require specialist psychiatric and health intervention. Challenging behaviour has led to an increased demand for specialist services.

What is ‘challenging behaviour’? The literature abounds with references to “challenging behaviour” in the context of intellectual disability. Other terminology, which refers to a person having “high and complex needs” or “very high support needs”, is usually a reference to a person with intellectual disability who demonstrates challenging behaviours or in some cases “seriously challenging behaviour”.

The term “challenging behaviour” itself provokes considerable comment and there are those who will argue its appropriateness or otherwise – though it is recognised as a fixture in the disability language and literature. Attempts have been made to define challenging behaviour in terms of the behavioural characteristics, aetiologies, quantifiable frequencies or severities. As a result, the term in practice is increasingly used as a diagnostic label, a means of describing groups of individuals or groups of behaviours. It is also used to describe specialist services or service elements and professional roles, with the result, some argue, that people with learning disabilities become labelled by association.

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4 Pg 13, Challenging Behaviour: A Unified Approach – Clinical and Service Guidelines for Supporting People with Learning who are at Risk of Receiving Abusive or Restrictive Practice, College Report, CR 144, June 2007
Indeed, the term ‘challenging behaviour’ was introduced in North America in the 1980s, by members of TASH (The Association for People with Severe Handicaps) and was adapted in the UK by an ‘Ordinary Life’ working party which met at the King’s Fund Centre. The intention was to focus on those who challenge services. The idea behind the use of this term is that it is meant to be less stigmatising than labels such as ‘behavioural disturbance’, ‘problem behaviour’, ‘maladaptive behaviour’, ‘aberrant behaviour’ and ‘behavioural abnormalities’.

In addition these later terms can be misleading - for example behaviours that persons may see as maladaptive can in some instances be adaptive for the person with a learning disability who displays them. A person who uses challenging behaviour as a means of communication as he or she may have limited other means to communicate is a good illustration of this. Moreover, identical behaviour may be seen as challenging by staff in one setting but not in another. Different interpretations of challenging behaviour have a major impact on prevalence figures.

The most commonly cited definition of Challenging Behaviour in the literature is:

“Culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities”.

All behaviour has meaning or function and does not occur in isolation. There are likely to be a number of underlying causes of behaviour that are a challenge to others. As well as functional determinants, precipitants and maintaining factors, aetiologies may include:

- Physical: discomfort, pain, malaise, physiological disturbance (e.g. thyroid disorders).

- Mental illness: mood disorders, psychosis, anxiety, obsessive–compulsive disorders.

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- Neuropsychiatric disorders: epilepsy, Gilles de la Tourette syndrome, attention-deficit hyperactivity disorder (ADHD), dementia.

- Pervasive developmental disorders: autism.

- Phenotype-related behaviours: Prader-Willi syndrome, Lesch-Nyhan syndrome, Williams syndrome.

- Psychological trauma: reaction to abuse or loss.

- Communication difficulties: hearing loss, unclear communication.

- Insufficient vocabulary or means of expression, difficulties understanding communication of others.

02.2 Prevalence and Manifestation of Challenging Behaviour

It is to be noted that literature shows that only a relatively few studies have attempted to identify the prevalence of multiple forms of challenging behaviour among a total population sample (i.e. all disabled people with challenging behaviour living in a defined area). More commonly, studies have focused on either specific topographically defined sub-types of challenging behaviour, such as self-injurious behaviour or aggression, or have restricted sampling to specific subpopulations of people with learning disability, for example those living in institutional and community settings.\(^7\)

The Hester Adrian Research Centre (HARC) undertook a large-scale study of the prevalence of challenging behaviour in the areas served by seven District Health Authorities in the North West of England in 1988. This study screened approximately 4,200 people with learning disability and identified people as showing severe challenging behaviours if they had either\(^8\):

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\(^8\) Ibid
- At some time caused more than minor injury to themselves or others, or destroyed their immediate living or working environment; or

- showed behaviours at least once a week that required the intervention of more than one member of staff to control, or placed them in danger, or caused damage which could not be rectified by care staff, or caused more than one hour's disruption; or

- Showed behaviours at least daily that caused more than a few minutes disruption.

Using this definition, 1.91 people per 10,000 of the general population (range 1.41 to 2.55 per 10,000 across the seven areas) were identified as having a learning disability and severe challenging behaviour. This translates to an estimated prevalence rate of 5.7% of all people within these areas who had been administratively defined as having a learning disability.\(^9\)

Emerson and Bromley\(^{10}\), using closely parallel methods in another area of North West England, identified 3.33 people per 10,000 of the general population as having a learning disability and severe challenging behaviour (equivalent to approximately 7.8% of the people with learning disability who were screened).

Chung et al\(^{11}\) found that the prevalence rate in reported studies usually fell between 8% and 38% of the surveyed population of people with learning disabilities. The United Kingdom and United Studies studies of prevalence rates of challenging behaviour by Quershi\(^{12}\), Emerson\(^{13}\), and Borthwick-Duffy\(^{14}\), show that for every 100,000 of the general population, there are between 24 and 63 people on average who have an intellectual disability and seriously challenging behaviour.

\(^9\) Ibid
Studies which have focused on the prevalence of particular forms of challenging behaviour provide a more detailed breakdown of topographical variants of general classes of challenging behaviours. Prevalence rates of problem behaviour among individuals with developmental disabilities in the United States range from 2-28% for aggression, 10-31% for self-injury, and 7-30% for property destruction, with rates consistently higher for individuals with more severe difficulties and those who are diagnosed with autism. Levels of severity can range from relatively minor and brief to very severe, chronic, and potentially life-threatening. 15

McClintock, K et al,16 for example, show that results indicate that males are significantly more likely to show aggression than females and that individuals with a severe / profound degree of intellectual disability are significantly more likely to show self-injury and stereotypy than individuals with a mild / moderate degree of intellectual disabilities. Individuals with a diagnosis of autism are significantly more likely to show self-injury, aggression and disruption to the environment whilst individuals with deficits in receptive and expressive communications are more likely to show self-injury.

Among individuals with developmental disorders who display self-injurious behaviour, head-hitting and head-banging are among the most commonly reported forms. Other forms of self-injurious behaviour include self-biting, body-hitting, self-scratching, and eye-poking. Injuries that have been documented to result from self-injurious behaviour include soft tissue injury, lacerations, contusions, infections, permanent scars, callus formation, and permanent damage to the eye such as retinal detachment. These injuries sometimes require suturing of lacerations, skin grafts to replace damaged tissue, and retinal reattachment surgery. 17

Aggressive behaviour such as biting, hair-pulling, hitting, choking, punching, and head-buttting can also be severe. Aggression is the most common form of problem behaviour leading to referral of people with developmental disorders for specialised treatment, and is

16 Pp 405-416McClintock, K., Hall, S., and Oliver, C., Risk Markers Associated with Challenging Behaviour in People with Developmental Disabilities: A Meta-analytical study, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, Journal of Intellectual Disability Research, 47
one of the main barriers to placement in integrated educational and community settings. It is also associated with high service costs and high staff turnover rates in service programs.\(^{18}\)

In a longitudinal study that involved 215 families with a child with learning disability, aged three to five years old, it was found that challenging behaviour was high. The study found that 38.2% of three year old children scored within the borderline or clinical range on the Child Behaviour Checklist for total behaviour problems, compared with 10.3% of typically developing children. They also found that behaviour problems differed by syndrome, with the highest levels being found among children with autism and cerebral palsy. Children with Down syndrome were similar to typically developing children, showing the lowest levels of behaviour problems.\(^{19}\)

Further research shows that school-aged children and adolescents with a learning disability are at increased risk of psychiatric disorders.\(^{20}\) In an epidemiological study, Emerson analysed a national dataset of diagnostic information from over 10,000 children aged 5-15 years in Great Britain.\(^{21}\) The study found that 39% of children with learning disability met the criteria for at least one psychiatric diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders and International Classification of Diseases compared with only 8.1% of children without learning disability. It was found that children with learning disability were at particular risk of Attention Deficit Hyperactivity Disorder (ADHD), conduct disorder, anxiety disorders and pervasive developmental disorders.

The overall prevalence of challenging behaviour increases with age during childhood, reaches a peak during the age range 15-34 and then declines. When comparisons are made with the age structure of the total population of people with learning disability it is apparent that challenging behaviours appear to be particularly over-represented in the 15-24 age group. This progression is more complicated, however, when the prevalence of particular forms of challenging behaviour is examined. Oliver et al, for example, report that while multiple topographies, head to object banging, head punching and finger chewing are significantly

\(^{18}\) Ibid
more prevalent in younger people with self-injurious behaviour, skin picking and cutting with tools are more prevalent among older people.22

Thus the prevalence of challenging behaviour can be conceptualised within such parameters as
- number of individuals excluded from local services
- number of individuals in ‘out of area’ placements
- number of individuals not receiving day services, employment
- opportunities, education, respite or home support
- service responses involving challenging behaviour
- seclusion
- restraint
- abuse
- clinical responses involving challenging behaviour
- punitive and aversive behavioural interventions
- risk avoidance rather than risk management.23

02.3 Support Needs for Persons with Challenging Behaviour

People with challenging behaviour will have a variety of needs that are a direct result of impairments in their intellectual and adaptive functioning. The implications of having a challenging behaviour will vary from individual to individual, according to their cognitive profile, daily living skills, level of intellectual impairment and previous learning experiences.

There are, however, common difficulties that exist for people with a learning disability on the basis of their significant and global intellectual impairment. People with challenging behaviour and an intellectual impairment are like to have impairments in verbal comprehension, perpetual reasoning and perpetual organisation, working memory, and processing speed.

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23 Pg 14, Challenging Behaviour: A Unified Approach – Clinical and Service Guidelines for Supporting People with Learning who are at Risk of Receiving Abusive or Restrictive Practice, College Report, CR 144, June 2007
Training of key persons who play a major role in the life of a disabled person with challenging behaviour, such as for example parents and siblings, to provide an appropriate environment for the person with the condition is important. These key persons should interact with the disabled person with challenging behaviour on a daily basis in ways that promote appropriate development and reduce the occurrence of challenging behaviours. In particular, it is important for the key persons to foster particular skills, especially communication skills, because an absence of these skills increases the risk of challenging behaviours.  

Yet, evidence suggests that families may have significant difficulties in accessing effective support and that there are often substantial difficulties in translating external support into practice in community-based residential services. Support to families of children with challenging behaviour should be directed towards providing specialist support to people with challenging behaviour with regards to the:

- The balance of activity of support services between supporting people living in family settings and supporting people in residential care.

- The competencies of specialised support services working with families.

- Arrangements developed by local providers for managing the interface between community-based services and specialised support services.

The HARC survey suggested that very few people with challenging behaviour had access to any form of vocational activity and that a very substantial minority of people with challenging behaviour had no access to any form of day service and recommended that the provision of day support to people with challenging behaviour should be directed towards:

- Identifying and removing barriers to people with challenging behaviour accessing existing vocational programmes.

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24 Pg 9, Evidence Based Guidelines to Reduce the Need for Restrictive Practices in the Disability Sector, Australian Psychological Society, 2011


- Identifying opportunities for developing additional vocational programmes for people with challenging behaviour.

- Monitoring the numbers and situation of people with challenging behaviour who have no day service.

- Establishing clear mechanisms for ensuring that all people with challenging behaviour have access to a day service.\(^\text{28}\)

Additionally, the HARC survey indicated that fewer than 10% of people with challenging behaviour had access to an advocate. It was subsequently argued that given that (i) challenging behaviour tends to be more prevalent among people with more severe learning disabilities; and (ii) people with challenging behaviour are at greater risk of abuse it was recommended that local advocacy services that specifically target people with challenging behaviour are introduced.

02.4 Provision of Services to Persons with Challenging Behaviour

Behaviours of concern are often complex. Interdisciplinary collaboration amongst professionals from speech pathology, occupational therapy, physiotherapy, psychiatry or general practice, therefore, provide a richer understanding of the unmet needs that underlie these behaviours and can lead to a more effective approach in developing appropriate interventions in aspects such as:

- Adapting the person’s environment.

- Developing meaningful tasks and enjoyable activities.

- Developing skills training plans.

- Specialist assessments (e.g., sensory, communication, dysphagia, and equipment needs).

\(^{28}\) Pg 26, Ibid
- Adaptation and making of appliances where mechanical restraint is required to minimise injury to the person.

- Staff training in specialist areas (e.g., communication and use of visual supports).

Thus, speech pathologists when working with people who have behavioural challenges, focus on developing the person’s communication skills to replace the behaviour and provide a functional equivalent to the behaviour of concern. Their contribution can also be to increase the skills of key persons in the life of the disabled person with challenging behaviour so that he or she becomes a more effective communication partners with the person, to become better at identifying the person’s early warning signs, and to enhance positive interactions between the parent, or the staff, and the person. In addition, speech pathologists have skills in assessing and providing interventions for people who have dysphagia (swallowing problems).  

When participating in the development of interventions to address behaviours of concern, occupational therapists place emphasis on exploring the context of the person’s behaviour, rather than simply prescribing aids and devices to be used as restraints or to reduce risk of injury. Particular areas of focus for occupational therapists are environmental analysis, injury prevention and engagement. Occupational therapists may also have specific expertise in assessing people’s sensory needs and developing intervention strategies to address sensory integration or dysfunction issues that may be contributing to the behaviours of concern. Skilled and experienced occupational therapists can work collaboratively with physiotherapists as well as psychologists in addressing the equipment needs of people with more severe behaviours of concern that place a person’s safety and well-being at risk.

The traditional role of physiotherapists (postural problems, lower limb deformities, and wheelchair and insert prescription) has evolved to a greater emphasis on consultation and collaboration with people from other disciplines. This applies particularly to issues of restrictive practices and ‘grey areas’. Grey areas involve interventions and devices where,

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29 Pg 17, Evidence Based Guidelines to Reduce the Need for Restrictive Practices in the Disability Sector, Australian Psychological Society, 2011
30 Ibid
although the focus is on safety, injury prevention and reduction of risk, the functional impact on the disabled person is one of restraint and restriction of freedom of movement.

Similar to occupational therapists, skilled and experienced physiotherapists explore referrals further than simply considering equipment needs. They too look at a person’s whole situation, what social issues may be impacting on the referral problem, and how any prescribed therapy or equipment can assist the person as well as others in the person’s environment.31

Studies investigating the effect of training on care-staff perceptions show, unsurprisingly, that there is a consistent effect of training programmes aimed at changing staff understanding of challenging behaviours on perceptions of challenging behaviour. Studies investigating effects of training show changes in perceptions of challenging behaviour that is more in line with the described theoretical perspective of the training course. There appears to be greater effect with longer courses, but there are also changes in perceptions following very short courses.32

McKenzie et al (2004), as quoted by Crossland (2009) also show an effect of the general education of nurses on the perceptions of challenging behaviour. They found that third year students are more likely to attribute passive behaviour and aggression to internal factors than first or second year students. Further to this, compared to first and second year students, third year students are more likely to think that stereotyped behaviour is stable.33

The longer courses comprised one longitudinal course on multi-element behaviour support with nine contact days (Grey et al., 2002), one two year diploma on Positive Behaviour Support with 29 contact days (McGill et al., 2007) and one open learning course on Approaches to People with Challenging Behaviour (Campbell and Hogg, 2008). Grey et al. (2002) found that there were significant changes in the number of staff endorsing negative reinforcement, positive reinforcement and self-stimulation as causal explanations for the challenging behaviour following training.34

31 Ibid
32 Pg 28, Crossland, R. T., Care Staff Perceptions of Challenging Behaviour in Adults with Autism and Learning Disabilities, University of Hull, July 29
33 Ibid
34 Ibid
Self-injurious behaviours not only cause harm to people who engage in them; they also cause significant psychological distress to staff providing support. Indeed, it is widely accepted that working with people with learning disabilities can be stressful for direct care staff: research suggests that as many as one third of staff members in services to persons with challenging behaviour may experience stress levels indicative of a mental health problem.\(^{35}\)

In addition to adverse effects on staff mental and physical health, staff stress can impact on the delivery and quality of services for people with challenging behaviour. Stress has been linked to staff turnover and absenteeism which affects the consistency of care of children and adults with challenging behaviour. Moreover, there is evidence to suggest that staff under stress engage in fewer positive interactions with disabled persons and in extreme cases lose all sensitivity for their disabled persons.\(^{36}\)

Jenkins et al compared the well being of staff in community residences for people with learning disabilities who exhibit challenging behaviour with that of staff not working with disabled persons with challenging behaviour. The analysis reveals significantly higher levels of anxiety in staff working with disabled persons who exhibited challenging behaviour than in staff working in residences where challenging behaviour is not considered a feature.\(^{37}\)

Research has shown that negative psychological symptoms are common amongst staff following physical and verbal aggression. These symptoms can range from minor, transient emotional distress including feelings of anger, stress and depression to severe and long-lasting symptoms of anxiety consistent with a diagnosis of post-traumatic stress disorder. The negative sequelae of patient aggression can have a knock-on effect upon staff morale and may impact upon recruitment and retention in the workplace.\(^{38}\)

### 02.5 Impact of Challenging Behaviour on Parents

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\(^{35}\) Pg 2, Jenkins, K., Psychological Correlates of Well Being in Direct Care Staff in Services for Children with Intellectual Disabilities and Challenging Behaviour, University of Southampton, May 2009

\(^{36}\) Pp 267-277, Rose, J., David, G., and Jones, C., Staff who work with people who have intellectual disabilities: The importance of personality, Journal of Applied Research in Intellectual Disabilities, 16


\(^{38}\) Pg 22, Parry, J., C., Understanding Patient Aggression: An Experimental Study of Psychiatric Nurses’ Attributions for Patient Aggression and their Relationship to Staff Well-being, University of Edinburgh, August 2007
Research has suggested that parent behaviour can influence a person’s outcomes in terms of a reduction in challenging behaviour. Specifically, research suggests that negative parenting interactions such as harsh, negative or inconsistent behaviours can predict future negative outcomes in terms of challenging behaviour for children: for example, Onufrait et al demonstrate that parental stress is linked to less responsive parenting, less effective uses of directives, and subsequent poor development in high-risk premature infants. In addition, it has been found that challenging behaviour can be considered aversive to parents. Due to this, parents may try to avoid the behaviours and inadvertently reinforce them. Parents under stress may be less tolerant of challenging behaviour and possibly avoid active attempts to manage the behaviour.

Many studies have illustrated that parents of a child with a learning disability are likely to experience significantly higher levels of parenting stress than are parents of typically developing children. Despite these broad findings, it is also acknowledged that parents of a child with a learning disability vary considerably in the levels of stress they experience. As well as evidence for the association between the frequency and severity of behaviour problems in families who have a child with a learning disability and parental stress and mental health problems, there is also evidence that it is the child behaviour problems that predict parental stress and not the learning disability itself.

43 Pg 9, Patterson, A., A., The Effectiveness of Combined Stress Control and Behaviour Management Sessions for Parents who have a Child with a Learning Disability, University of Edinburgh, 2010
03. Methods

The information presented in this report is on the basis of two population samples:

100 disabled persons with challenging behaviour or their primary care givers.

100 persons working with persons with challenging behaviour.

The approach adopted for both target populations is the following:

The JV designed the draft questionnaire for each target population and submitted it for discussion and review by KNPD.

The original questionnaires presented for each target population were, following discussion, shortened from the original version submitted and some amendments were incorporated by KNPD.

A consent form was presented to KNPD which was subsequently presented by the interviewers to the parent, staff member or disabled person, as the case may be, for signature prior to the initiation of the interview. A copy of the consent form is presented in Appendix I.

Each questionnaire was piloted with 15 persons from each target population.

The results of the pilot studies were analysed and discussed with KNPD. It was agreed that no amendments were required.

The carrying out of the full research with the remaining 85 sample population in each respective category.
With regard to the carrying out of the research the following is to be noted:

A lead coordinator (PhD) was assigned to manage the interviewers and assure the quality process.

Four interviewers were assigned for the face-to-face interviews. These interviewers underwent a short training programme held by KNPD directed to provide induction disability equality training.

An interview log was maintained on a spreadsheet and this was audited by the lead coordinator on a periodic and random basis for data integrity.

SPSS Statistics 20 was used to analyse the results.

03.1 Interview of Disabled Persons with Challenging Behaviour or their Primary Care Givers

On the direction of KNPD, the researcher issued an invitation letter to a list of care service providers identified by KNPD kindly requesting them to provide to the researcher the following:

- Names of disabled persons with challenging behaviour or their care giver from Malta and Gozo who will provide their consent to participate in both a Pilot Test and the actual research itself.

- Addresses and contact numbers so that identified persons could be approached by the researcher to organise the face-to-face interview meetings.

It is to be noted that the identification of the 100 sample population of disabled persons or their primary care givers was an issue that had an impact on the timeframe for the completion of the research study.
A number of the parents approached to participate in the survey either refused or initially accepted but subsequently turned down the invitation to participate when informed that the research focused on persons with a ‘challenging’ behaviour condition - in instances, it is pertinent to underline, that parent or staff members specifically stated that they do not consider their son or daughter to have a ‘challenging behaviour’ condition.

Given the difficulties experienced in this regard, the researcher solicited the support of KNPD to approach parents or staff members in order to convey the legitimacy of the research underway as well as to seek their participation given that research is directed to assist person with such a condition as well as their families.

Where so appropriate, the face-to-face interviews were carried out at the KNPD premises in Santa Venera – although where so requested interviewers met the interviewees at their place of residence. With regards to disabled persons who live in an institutional household, the interview was held at the residence and in most instances the interview was held with the staff member.

Of the 119 parents or primary care givers approached, the final 100 person sample population was constituted of disabled persons or their primary care givers identified through eight service providers. The names of the care service providers are not presented in Figure 01 for privacy purposes.

It is, pertinent to underline that the difficulties encountered with parents to participate in the research is reflective of the concern shown in international literature where parents of disabled persons with challenging behaviour fear that the term “challenging behaviour” may stigmatise their son or daughter and consider it as a ‘negative label’.

One direct impact on the research as a result of this issue is that the target population in agreement with KNPD, was identified by direct means rather than on the basis of a sampling methodology.
The questionnaire, a copy of which is presented in Appendix II, consisted of 10 questions. The information was collected on:

The relationship between the primary care giver and the disabled person with challenging behaviour, the age, gender and the locality from which the said disabled person comes from, and where the disabled person resides.

The type of the impairment and / or condition and the assistance required by the disabled person with challenging behaviour.

The place or activity that occupies the disabled person with challenging behaviour primarily during the day, whether he or she carried out a social and recreational activity, whether he or she has access to advocacy and the overall satisfaction level with regard to the services provided.

Open question with regard to the rating given to the satisfaction level as well as matters that the interviewee wished to contribute on.

It is to be noted that of the sample of 100 disabled persons, only 2 persons with challenging behaviour directly participated in the interview and answered the questions themselves. With
regard to the other 98 persons, the respondents are either parents, relatives or staff members as the case may be.

03.2 Interview of Staff Members Working with Disabled Persons with Challenging Behaviour

The staff members were approached on the basis of a list, presented to the researcher by KNPD, of support organisations which provide care support to persons with challenging behaviour. The questionnaire, a copy of which is presented in Appendix III, consisted of 16 questions. The information was collected on:

- The length of experience in the provision of care to disabled persons with challenging behaviour, the job title, and the length of care provided to his or her disabled person.

- The level of education, further specialised education embarked upon, extent of preparation as a result of such training, their understanding of the term ‘challenging behaviour’ and their level of confidence in working with such persons.

- The impairment of his or her disabled person, the daily activity needs of the disabled person, whether certain approaches to care have positive results on the disabled person.

- Open questions with regard to what helps or facilitates as well as hinders the inclusion of a disabled person in accessing services.

Difficulties were also encountered with regard to the sample particularly due to the myriad of service providers and a level of fragmentation. Indeed, this part of the research was achieved once the larger number of service providers and their staff members were engaged.

The interviews were carried out at the place from where the staff members provided their services. The staff members interviewed were identified from thirteen support services – the name of which are not presented in Figure 02 for privacy purposes.
Figure 02: Staff Members Sample Representation
04. Results

Chapter 04

04.1 Persons with Challenging Behaviour or their Primary Care Givers

04.1.1 Age, Gender and Locality of Disabled Persons Surveyed

The Table below demonstrates the gender composition of the target population related to disabled persons or their primary care givers.

Figure 03: Profile of Disabled Persons by Gender

As can be seen from the Table above, 60% of the target population are males whilst 40% are females.

Table 02 below presents the age composition of the target population. As can be seen from this Table 85% of the population constitutes of disabled persons within the age groups of 0 to 39 years respectively – with the number of disabled persons within the respective age group being approximately equal.
Of the remaining age groups, only 4% constitute of disabled persons who are 60 years and over – with the remaining 11 disabled persons being within the age group of 40 to 59 years.

**Figure 04: Profile of Disabled Persons by Age**

As is shown in Figure 03, 10 out of 15 of the disabled persons in the age group between 40 of age to 70 years are female – or 66.6% of the disabled persons within this cohort. On the other hand, 55 of the 85 persons in the age group between 0 to 39 years are male – or 64.7% of the disabled persons in this age cohort.

**Figure 05: Profile of Disabled Persons by Age and Gender**
The localities are classified in Regions in accordance with the Malta Geographical Code as follows:

<table>
<thead>
<tr>
<th>Region</th>
<th>Localities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Southern Harbour</td>
<td>Żabbar, Xghajra, Valletta, Tarxien, Santa Luċija, Paola, Marsa, Luqa, Kalkara, Senglea, Floriana, Fgura, Cospicua, Vittoriosa.</td>
</tr>
<tr>
<td>Northern Harbour</td>
<td>Ta’ Xbiex, Swieqi, Sliema, Santa Venera, San Ġwann, St.Julians, Qormi, Pieta’, Pembroke, Msida, Hamrun, Gżira, Birkirkara.</td>
</tr>
<tr>
<td>South Eastern</td>
<td>Żurrieq, Žejtun, Safi, Qrendi, Mqabba, Marsaxlokk, Marsascala, Kirkop, Gudja, Ghaxaq, Birżebbuġia.</td>
</tr>
<tr>
<td>Western</td>
<td>- Żebbuġ, Siġġiewi, Rabat, Mtarfa, Mdina, Lija, Iklīn, Dingli, Balzan, Attard.</td>
</tr>
<tr>
<td>Northern</td>
<td>St. Paul’s Bay, Naxxar, Mosta, Mgarr, Mellieha, Gharghur.</td>
</tr>
<tr>
<td>Gozo and Comino</td>
<td>Rabat, Fontana, Ghajnsielem and Comino, Gharb, Ghasri, Kerċem, Munxar, Nadur, Qala, San Lawrenz, Sannat, Xagħra, Xewkija, Żebbuġ.</td>
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</tbody>
</table>

The locality with the highest number of disabled persons is the Southern Harbour Region (29%). This is followed by the Northern Harbour Region and the Northern Region respectively – both with an 18% representation of the total population. These three Regions, therefore, constitute 65% of the entire population surveyed.
The total number of disabled persons who reside in Gozo are 13.

As can be seen from the Figure below 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 age group between 30 years to 70 years and over, 5 are female or 38.46% of the Gozo sample - or 5% of the total sample.
04.1.2 Place of Residence of Disabled Persons Surveyed

Seventy-four percent of the disabled persons live at home with their parents or relatives whilst 26% live in a residence or in an institution or in a supported environment.

It is to be noted that none of the disabled persons surveyed live in Community Based Homes. Out of the female population surveyed, 62.5% live with their family in comparison with the 81.6% of the male population.
As can be seen from the Figure below, of the population sampled 60% who live with their family are between 0 and 29 years of age. There are only 3 disabled persons in the 40 years age group and over who live with their family. The incidence of disabled persons living in a residence or institution seems to increase with age.
With regard to the disabled person population that resides in Gozo, 12 live with their family and 1 lives in a supported environment. The person who lives in Gozo and resides in a supported environment is male and in the age group of 40 years to 49 years.

**Figure 12: Where Disabled Persons who Live in Gozo Reside**

![Bar chart showing the distribution of disabled persons living in Gozo](image)

<table>
<thead>
<tr>
<th>Residence Type</th>
<th>Count</th>
</tr>
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<tbody>
<tr>
<td>Live with Family</td>
<td>12</td>
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<tr>
<td>Live in Institutional</td>
<td>1</td>
</tr>
<tr>
<td>Household</td>
<td></td>
</tr>
<tr>
<td>Live in Community Based Homes</td>
<td>0</td>
</tr>
</tbody>
</table>

**04.1.3 Relationships of Disabled Persons with the Primary Care Giver**

Figure 13 below demonstrates the relationship between the disabled person and the primary care giver. As can be seen, parents act as the primary care givers for 70% of the disabled persons; where-in with regard to a further 5% of the disabled persons it is a relative of the disabled person who is the primary care giver.
With regard to the remaining 26 disabled persons, the primary care giver is a staff member. As can be seen from the Figure below, the male disabled persons who live in a Supported Environment are assisted by their parents, and one male disabled person who lives with his parents is supported by a staff member.

As can be seen, with regard to disabled persons who reside in Gozo, 12 live at home with their family, and hence, their parents who their primary care givers. The other male disabled person, although residing in a Supported Environment, has his parents as his primary care givers.
04.1.4 Condition and / or Impairment of Disabled Person

In analysing the conditions and / or impairment that disabled persons have it is to be noted that amongst the population surveyed disabled persons have 132 conditions and / or impairments: which means that a number of disabled persons have more than one condition and / or impairment.

The most prevalent condition and / or impairment is Autism – which is seen to be present 42 times – or 31.8%. Autism, Intellectual Impairment and Down Syndrome are seen to occur 63 times – or 47.7% of the total number of conditions and / or impairments that disabled persons have.
As shown in the Figure below, 73 of the disabled persons have 1 condition and / or impairment; 22 have 2 conditions and / or impairments; and 5 have 3 conditions and / or impairments.

The age and gender profile of disabled persons who have 1 condition and / or impairment reflects that of the total sample (n=100) as each disabled person has, at least, one condition and / or impairment.
Of the 73 disabled persons who have one condition and/or impairment, 34 have Autism. It is to be noted that 50 of the disabled persons (68.5%) have Autism, Down Syndrome, or an Intellectual Impairment.

**Figure 18: Disabled Persons who have One Condition and/or Impairment Only**

As can be seen from the Figure below the highest category of disabled persons who have one condition and/or impairment are in the age group of 0 to 9 years (18 times) followed by disabled persons in the age group of 10 to 19 years (16 times). Forty-four (or 60.2%) of the disabled persons who have one condition or impairment are male.
Table 1 shows the number of persons who have 2 conditions and / or impairments as well as the type of condition and / or impairment. The 22 disabled persons who have 2 conditions and / or impairments cover 17 of the full range (21) of conditions and impairments observed. As can be seen from the Table below given the broad range of conditions and / or impairments it is difficult to identify trends. 4 of the disabled persons (n=22) in cohort have Autism, of whom 2 also have an ‘Other Mental Illness’ condition. The remaining 2 also have an ‘Epilepsy and / or Fits’ condition.

Two of the disabled persons who have an ‘Other Mental Illness’ condition also have a Verbal Impairment, whilst a further 2 have a Mobility Impairment. The two disabled persons who have a Schizophrenia condition also have Learning Disability.
Table 1: Representation and Type of Conditions and / or Impairment of Disabled Person Cohort Group with Two Conditions and / or Impairments
<table>
<thead>
<tr>
<th>Schizophrenia</th>
<th>Learning Disability</th>
<th>Autism</th>
<th>Intellectual Impairment</th>
<th>Other Mental Illness</th>
<th>Hearing Impairment</th>
<th>Verbal Impairment</th>
<th>Down Syndrome</th>
<th>Visual Impairment</th>
<th>Dopa Responsive Dystonia</th>
<th>ADHD</th>
<th>Duchenne Muscular Dystonia</th>
<th>Mobility Impairment</th>
<th>Cerebral Palsy</th>
<th>Brain Damage</th>
<th>Epilepsy / Fits</th>
<th>Other</th>
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</table>
The Figure below shows the age and gender profile of the cohort group that has 2 conditions and / or impairment. As can be seen, disabled persons who are in the age group of 30 to 39 years constitute the largest group with 2 conditions and / or impairments. Males constitute 56.5% of the said population.

**Figure 21: Disabled Persons who have Two Conditions and / or Impairments**

![Figure 21: Disabled Persons who have Two Conditions and / or Impairments](image)

As can be seen from Table 2, 5 disabled persons have 3 conditions and / or impairments. Of these, 3 have Autism, of whom 2 have an ‘Other Mental Illness’ condition. One of these has a third condition which is ‘Visual Impairment’; which is also an impairment held by a disabled person who also has Autism.

**Table 2: Disabled Persons who have Three Conditions and / or Impairment**

<table>
<thead>
<tr>
<th></th>
<th>Autism</th>
<th>Intellectual Impairment</th>
<th>Other Mental Illness</th>
<th>Visual Impairment</th>
<th>Cerebral Palsy</th>
<th>Prader Willi Syndrome</th>
<th>OCD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

Three of the disabled persons who have 3 conditions and / or impairments are male: each within the age groups of 10 to 19; 20 to 29; and 30 to 39 years respectively. The 2 female
disabled persons who have 3 conditions and / or impairment are within the age groups of 10 to 19 and 20 to 19 years respectively.

The Figure below shows that out of the sample population of disabled persons who reside in Gozo, 11 have 1 condition and / or impairment whilst 1 disabled person has 2 conditions and / or impairment and 1 other disabled person 3 conditions and / or impairment.

**Figure 22: Disabled Persons in Gozo with Conditions and / or Impairment**

The Gozitan disabled person who has 2 conditions and / or impairments is male and is in the age group of 40 to 49 years. The primary care giver is the parent and the person resides in a supported environment. The conditions of this disabled person are Autism and Epilepsy. The disabled person who has 3 conditions and / or impairments is female and is in the age group of 20 to 29 years. The person lives with her parents – who are the primary care givers. The conditions of this disabled person are Autism, Intellectual Impairment and Visual Impairment.

**04.1.5 Manifestation of Challenging Behaviour**

It is pertinent to underline that with regard to 8 disabled persons it is reported that the said disabled persons did not, at time of the survey, have challenging behaviour. The reasons for this are primary twofold. In most cases it is stated by the interviewee that the disabled person does not have challenging behaviour. Otherwise it is stated that either the disabled person is under new medication which has a soothing affect on the disabled person or at the time of the interview the disabled person was not experiencing a challenging behaviour manifestation.
The disabled persons who experience one or more manifestation number 92. In all, this cohort of disabled persons (n=92) experience a total of 134 types of manifestation. This means that a number of disabled persons experience more than one single manifestation of challenging behaviour.

Of particular note is that the most prevalent manifestations are Aggression – with Physical standing at 36, Verbal at 14 and General – which is defined to mean mild or occasional manifestations of aggression – at 17: that is, Aggression as a manifestation is evidenced 65 times – or 50.7%.

Figure 23: Total Number of Manifestations Identified

As can be seen from Figure 24, 59 of the disabled persons surveyed experience 1 manifestation; 22 experience 2 manifestations; whilst 8 and 3 disabled persons experience three and four manifestations respectively. There are no disabled persons who experience more than four manifestations.
As can be seen from the Figures below the majority of disabled persons who experience two to four manifestations of challenging behaviour are in the age group of 0 to 39 years. There is only one disabled person in the age group of 40 years and over who experiences more than three manifestations.

On the other hand, the number of disabled persons in the age group of 40 years and over who experience 2 manifestations, given their small representation (n=15) is 3 or 33.3%.
Figure 27 below shows the type of manifestations experienced by disabled persons with one manifestation. The highest type of manifestation is ‘Other’ – which includes, but is not limited to manifestations such as tantrums, hard headedness, possessiveness, agitation, lack of patience, mood swings, etc.

**Figure 27: Type of Manifestation of Disabled Persons who Experience One Manifestation**
Aggression, when clustered together, manifests itself in 27 disabled persons who experience one manifestation – or 45.7 of the sample population (n=59).

Of the 22 disabled persons who experience 2 manifestations, as can be seen from the Table below, 21 out of 22 have a form of Aggression as a manifestation. None of these disabled persons experience Paranoia as a manifestation.

Table 3: Disabled Persons who have Two Manifestations of Challenging Behaviour

<table>
<thead>
<tr>
<th>No of Persons</th>
<th>Disabled</th>
<th>%</th>
<th>First Manifestation</th>
<th>Second Manifestation</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>22.7%</td>
<td>Physical Aggression</td>
<td>Verbal Aggression</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>13.6%</td>
<td>Physical Aggression</td>
<td>Self Injury</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>4.5%</td>
<td>General Aggression</td>
<td>Self Injury</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>9%</td>
<td>Verbal Aggression</td>
<td>Self Injury</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>18.1%</td>
<td>Physical Aggression</td>
<td>Destructive</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>4.5%</td>
<td>General Aggression</td>
<td>Destructive</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>9%</td>
<td>Verbal Aggression</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>4.5%</td>
<td>Self Injury</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>13.6%</td>
<td>Physical Aggression</td>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

It is pertinent to note, that of the disabled persons who experience two manifestations, 16 – or 72.7% have only one condition and / or impairment – of whom, 5 have Autism, 3 Other Mental Illness, 3 Intellectual Impairment, and 1 Down Syndrome. Six disabled persons from this cohort have 2 conditions – the most prevalent being Other Mental Illness (3 times).
With regard to the second manifestation, 16 of the disabled persons have an aggressive, self-injurious or destructive manifestation of challenging behaviour.

Table 4 below shows the number of disabled persons who experience 3 manifestations of challenging behaviour. All of the disabled persons, with the exception of 2, experience a manifestation in the form of Aggression. Four disabled persons experience self-injury as a manifestation, whilst 5 are destructive.
Table 4: Disabled Persons who Experience Three Manifestations of Challenging Behaviour

<table>
<thead>
<tr>
<th>No of Disabled Persons</th>
<th>%</th>
<th>First Manifestation</th>
<th>Second Manifestation</th>
<th>Third Manifestation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>12.5%</td>
<td>Physical Aggression</td>
<td>Verbal Aggression</td>
<td>Self Injury</td>
</tr>
<tr>
<td>2</td>
<td>25%</td>
<td>Physical Aggression</td>
<td>Verbal Aggression</td>
<td>Destructive</td>
</tr>
<tr>
<td>1</td>
<td>12.5%</td>
<td>Physical Aggression</td>
<td>Self Injury</td>
<td>Other</td>
</tr>
<tr>
<td>1</td>
<td>12.5%</td>
<td>General Aggression</td>
<td>Self Injury</td>
<td>Other</td>
</tr>
<tr>
<td>1</td>
<td>12.5%</td>
<td>Physical Aggression</td>
<td>Destructive</td>
<td>Other</td>
</tr>
<tr>
<td>2</td>
<td>25%</td>
<td>Self Injury</td>
<td>Destructive</td>
<td>Other</td>
</tr>
</tbody>
</table>

It is to be noted that 1 of the disabled persons who experiences 3 manifestations has only 1 condition and / or impairment – Autism. Four of the said disabled persons experience two conditions and / or impairment – the most prevalent being Duchene Muscular Dystrophy. The remaining disabled persons experience 3 conditions – the most prevalent being Autism and Other Mental Illness (2 times).

Table 5 shows the number of disabled persons who have 4 manifestations of challenging behaviour. As can be seen, each of the 3 disabled persons are prone to physical aggression, whilst 2 of the said disabled persons also experience verbal aggression as a second manifestation and the third disabled person is prone to self injury. One of the disabled
persons expresses paranoia as a manifestation – which is the only instance this manifestation is observed amongst the total population surveyed (n=100).

**Table 5: Disabled Persons who Experience Four Manifestations of Challenging Behaviour**

<table>
<thead>
<tr>
<th>No of Disabled Persons</th>
<th>First Manifestation</th>
<th>Second Manifestation</th>
<th>Third Manifestation</th>
<th>Fourth Manifestation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Physical Aggression</td>
<td>Verbal Aggression</td>
<td>Paranoia</td>
<td>Self Injury</td>
</tr>
<tr>
<td>1</td>
<td>Physical Aggression</td>
<td>Verbal Aggression</td>
<td>Self Injury</td>
<td>Destructive</td>
</tr>
<tr>
<td>1</td>
<td>Physical Aggression</td>
<td>Self Injury</td>
<td>Other</td>
<td>Other</td>
</tr>
</tbody>
</table>

It is to be noted that 2 of the disabled persons who experience 4 manifestations have 2 conditions and / or impairments – and 1 of the disabled persons resides in a residence or institution. The other disabled person experiences 3 conditions and / or impairments. All of the conditions and / or impairments experienced are different. The other two disabled persons live with their parents – who are the primary care givers.

The disabled persons who reside in Gozo experience, in total, 16 type of manifestations. Three of the disabled persons state that they currently do not experience a manifestation. The largest category of manifestations experienced is ‘Other’ – followed by Physical Aggression (25%) and Destructive Behaviour (35%).
As can be seen from the Figure below 10 of the disabled persons who reside in Gozo have 1 manifestation. Two of the disabled persons experience 2 forms of manifestation whilst 1 Disabled Person experiences 3 different forms of manifestation. There are no disabled persons in Gozo who have 4 different manifestations of challenging behaviour.

Table 6 below shows the manifestations of those disabled persons in Gozo who experience 2 forms of manifestation. Each of the disabled persons experience Destructive Behaviour as one of the manifestations.
Table 6: Disabled Persons who Live in Gozo who have Two Manifestations of Challenging Behaviour

<table>
<thead>
<tr>
<th>No of Disabled Persons</th>
<th>%</th>
<th>First Manifestation</th>
<th>Second Manifestation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>50%</td>
<td>General Aggression</td>
<td>Destructive Behaviour</td>
</tr>
<tr>
<td>1</td>
<td>50%</td>
<td>Physical Aggression</td>
<td>Destructive Behaviour</td>
</tr>
</tbody>
</table>

The first disabled person is female and is within the age group of 60 to 69 years. The second disabled person is male and is within the age group of 0 to 9 years and also lives with his parents.

The disabled person who has 3 manifestations experiences Physical Aggression, Verbal Aggression and Destructive Behaviour. The disabled person is a female and is in the age group of 20 to 29 years. This disabled person also lives with her parents.

04.1.6 Where the Disabled Person Spends Most of His or Time

The Figure below shows where disabled persons spend most of their time during the day.

Figure 30: How Disabled Persons Spend their Time During the Day
Fifty three of the disabled persons spend their day time in Education. Of these 15 undertake training programmes that are carried out by support organisations and 38 attend formal education. It is to be noted that only 5 disabled persons with challenging behaviour undertake some form of employment of whom 2 are in open employment. Another 18 attend day centres. It is pertinent to note that 24 disabled persons spend their time at either home (9 persons), residential or supported environment (10 persons) or at an institutional home (5 persons).

The Figures below correlate Age and Gender with the activities disabled persons carry out.

**Figure 31: Age of Disabled Person and Activity**

As can be seen from the above Figure, the majority of the disabled persons in the age group of 0 to 9 and 10 to 19 years respectively attend school. Disabled persons in the upper teens within the age group 10 to 19 years start a transition into employment. Nevertheless, as can be seen clearly from the figure above only few disabled persons from their late teens onwards are in a form of employment – with the majority of the disabled persons who are 20 years and over spending their day either at a Day Centre or at home.
Of particular note is that the number of females who are inactive either by staying at home or in a residence is higher than males. Although there are more females than males in some form of employment, the number of males who are undergoing a form of training programme is higher than females. Given that each disabled person carries out one Activity, the age and gender profile is similar to the n=100 profile.

Further to the above, it is pertinent to underline that with regard to a number of disabled persons where the primary care giver is the parent (or relative) the interviewee stated that they take the disabled person for additional activities (therapy, training, etc) held by NGOs and with regard to a small number of others, that their son or daughter was periodically taken into care for a short time in a supported environment or residence.

Of particular note, however, is that of the 100 disabled persons sampled none attend any form of advocacy programmes.

42 of the disabled persons interviewed carry out a social and recreational activity. The range of social and / or recreational activities carried out is broad and it is not possible to identify a trend. The social and recreational activities mentioned include, but are not limited to:
Table 7: Examples of Social and / or Recreational Activities Carried out by Disabled Persons

<table>
<thead>
<tr>
<th>Social and / or Recreational Activity</th>
<th>Social and / or Recreational Activity</th>
<th>Social and / or Recreational Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary Work</td>
<td>Sports (Generic)</td>
<td>Football</td>
</tr>
<tr>
<td>Pottery</td>
<td>Swimming</td>
<td>Computer / iPad and Computer Games</td>
</tr>
<tr>
<td>Church and Feast Activities</td>
<td>Horse Riding</td>
<td>Reading</td>
</tr>
<tr>
<td>Prayer Group</td>
<td>Beach</td>
<td>Knitting</td>
</tr>
<tr>
<td>Walking</td>
<td>Gym</td>
<td>Music</td>
</tr>
<tr>
<td>Drama</td>
<td>Scuba Diving</td>
<td>Dancing</td>
</tr>
<tr>
<td>Crafts</td>
<td>Cooking</td>
<td>Drawing</td>
</tr>
</tbody>
</table>

The most prevalent are Swimming (8 times), Drawing (6 times), and Computer / iPad and Computer Games (6 times).
Slightly less than half of the disabled persons who reside in Gozo spend their time at their parents home or in a supported environment. One of the 5 disabled persons (n=100) who have a form of employment resides in Gozo. The remaining 6 disabled persons are in education. Five of the disabled persons who live in Gozo state that they carry out a social and or recreational activities – Prayer Group (2 times); Swimming (2 times); Gym (2 times); Parish and Band Activities (1 time) and Scuba Diving (1 time).

Given that the overwhelming response to the question on the overall satisfaction rating of the disabled persons with regard to the services offered is positive, this part of the analysis focuses on those responses that are not classified as ‘Positive’.

Two of the 5 respondents who are in a form of employment activity classify their satisfaction of the service as Mildly Positive (female and in the age group of 10 to the 19 years and in supported employment) and Negative (male and in the age group of 20 to 29 years and in sheltered employment).
With regard to training, 4 responded as follows:

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Response</th>
<th>Gender</th>
<th>Age</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>10 to 19</td>
<td>Mixed</td>
<td>Male</td>
<td>10 to 19</td>
<td>Mixed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Male</td>
<td>30 to 39</td>
<td>Negative</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Male</td>
<td>30 to 39</td>
<td>Negative</td>
</tr>
</tbody>
</table>

The responses of those disabled persons who attend a formal education service that is not classified as ‘Positive’ stands at 11 – or 61%; which is relatively high. These responses are classified as follows:

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Response</th>
<th>Gender</th>
<th>Age</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>0 to 9</td>
<td>Mildly Positive</td>
<td>Male</td>
<td>0 to 9</td>
<td>Mildly Positive</td>
</tr>
<tr>
<td>Female</td>
<td>0 to 9</td>
<td>Mixed</td>
<td>Male</td>
<td>0 to 9</td>
<td>Negative</td>
</tr>
<tr>
<td>Female</td>
<td>0 to 9</td>
<td>Mixed</td>
<td>Male</td>
<td>0 to 9</td>
<td>Negative</td>
</tr>
<tr>
<td>Female</td>
<td>20 to 29</td>
<td>Mildly Positive</td>
<td>Male</td>
<td>0 to 9</td>
<td>Mixed</td>
</tr>
<tr>
<td>Female</td>
<td>10 to 19</td>
<td>Negative</td>
<td>Male</td>
<td>10 to 19</td>
<td>Mixed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Male</td>
<td>20 to 29</td>
<td>Negative</td>
</tr>
</tbody>
</table>

As can be seen, 3 (27%) of the eleven respondents assess the service to be ‘Mildly Positive’ whilst another 4 have ‘Mixed’ feelings on the service provided. 4 (36.3%), however, assess the service as ‘Negative’.

Of those who attend the Day Centre services three respondents assess the service as ‘Mildly Positive’ (female who resides in Gozo within the age group of 30 to 39 years); ‘Mixed’ (male within the age group of 20 to 29 years); and ‘Unclear’ (male within the age group of 20 to 29 years).
Four of the disabled persons who live in a residential or institutional home classify the service as follows:

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Response</th>
<th>Gender</th>
<th>Age</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>30 to 39</td>
<td>Mildly Positive</td>
<td>Male</td>
<td>30 to 39</td>
<td>Mixed</td>
</tr>
<tr>
<td>Female</td>
<td>30 to 39</td>
<td>Mixed</td>
<td>Male</td>
<td>30 to 39</td>
<td>Negative</td>
</tr>
</tbody>
</table>

It is to be noted that the Gozitan female disabled person referred above is the only person amongst the disabled persons who reside in Gozo who did not provide a ‘Positive’ satisfaction level.

04.1.7 Daily Activity Needs Required

The survey shows that 24 of the disabled persons interviewed require no assistance to carry out their daily activity needs – although with regard to a number of the said disabled persons it was stated that they require different degrees of guidance or supervision.

The Figure below shows the age and gender distribution of this cohort of disabled persons. As can be seen from the Figure below, 15 (62.5%) of the persons stated to be Independent (with potential guidance and supervision) are in the age group between 0 to 19 years. A potential reason, therefore, of the high level disabled persons identified as independent in this age cohort is that the assistance required may not be that different from a typically developing child in the same age group.
It is pertinent to underline that 7 of the disabled persons who are Independent reside in Gozo.

The remaining 76 disabled persons require a total of 307 types of daily assistance – which, on average, means that 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=76) is shown in the Figure below. As can be seen, 52% of the daily need requirements result from three basic functions: washing; dressing and eating. Assistance in communications constitutes 26% of the daily needs requirements – which is expected given that the most prevalent condition and / or impairment is Autism.

It is, however, pertinent to note that Going Out constitutes 14% of the daily activity needs. ‘Others’ includes daily activities such as money management, etc.
As can be seen from the Chart below the highest number of daily activity assistance required by a disabled person is seven.

Although the day activities needs of the disabled person sample population is varied some trends emerge. Amongst 37 disabled persons, all require daily assistance in ‘Dressing and Washing’. Fourteen disabled persons require further daily assistance in ‘Eating’ whilst 7 disabled persons require further assistance with regard to ‘Going Out’.
Table 8: Disabled Persons and Grouping of Daily Needs

<table>
<thead>
<tr>
<th>Daily Activity Needs</th>
<th>Eating</th>
<th>Dressing</th>
<th>Washing</th>
<th>Going Out</th>
<th>Eating</th>
<th>Dressing</th>
<th>Washing</th>
<th>Going Out</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘n’</td>
<td>Eating</td>
<td>Dressing</td>
<td>Washing</td>
<td>Going Out</td>
<td>Eating</td>
<td>Dressing</td>
<td>Washing</td>
<td>Going Out</td>
</tr>
<tr>
<td>Going Out</td>
<td>Eating</td>
<td>Dressing</td>
<td>Washing</td>
<td>Going Out</td>
<td>Eating</td>
<td>Dressing</td>
<td>Washing</td>
<td>Going Out</td>
</tr>
<tr>
<td>‘n’</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1</th>
<th>14</th>
<th>Restricted</th>
<th>1</th>
<th>7</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>3</td>
<td>Expressive Communication</td>
<td>1</td>
<td>Communication</td>
<td>2</td>
</tr>
<tr>
<td>Incontinent</td>
<td>1</td>
<td>Communication</td>
<td>3</td>
<td>Communication</td>
<td>6</td>
</tr>
<tr>
<td>Going Out</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

With regard to the other disabled persons, it is difficult to bring out trends. For example, the following is the profile of disabled persons who require assistance in two daily activities:

**Daily Activity Needs**

| Going Out | Communication | 2 times |
| Going Out | Other |
| Eating | Restricted Receptive Communication | 3 times |
| Communication | Other |
| Restricted Receptive Communication | Going Out | 2 times |
| Communication | Washing |
| Dressing | Eating |
Of the disabled persons who reside in Gozo, 6 (46.2%) require assistance in their daily activity needs – with one disabled person requiring assistance with three needs; one with four needs; two with five needs; and two with seven needs. The profile of daily activities with which they require assistance is shown in the Table below.

Table 9: Profile of Daily Needs for which Support is Required

<table>
<thead>
<tr>
<th>Disabled Person</th>
<th>Toileting</th>
<th>Eating</th>
<th>Dressing</th>
<th>Washing</th>
<th>Restricted Expressive Comm</th>
<th>Restricted Receptive Comm</th>
<th>Going Out</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>4</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

04.1.8 Concerns and Issues Raised by Primary Care Givers

With regard to the open ended question on what improvements and / or concerns interviewees wish to express 71 respondents answered. 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 are residing in an institutional household.

Of those who responded most present more than one recommendation and / or concern. The statements expressed are shown here under in ascending order: starting by the number of times they were most raised by different interviewees.
If one had to look at the 5 issues that are raised most times, 16 respondents express that there is a need for more assistance from the State – ranging from general to specialised services as well together with the provision of general care support that will allow both parents to be in employment – which, it is underlined, given the limited support available, is not possible.

Respondents who raise this issue also state, most often, that there is a need for more free or subsidised support as their families face financial difficulties in seeking to secure that their son or daughter are provided with the utmost care – a state of play that is further accentuated by the fact that (too often) the mother is not in a position to assist with the family’s financial resources through employment as she invariably adopts the role of the primary care giver.

It is important to observe that 14 respondents raise the concern of what will happen to their son or daughter when they are too frail to take care of him or her or should they pass away. It is, also, pertinent to underline, that the absence of support and facilitation of extracurricular as well as social and recreational activities is seen to constitute a major obstacle and a potential factor for a disabled person’s increased aggression as the frustration levels of the disabled person with challenging behaviour is seen to increase due to lack of activity due to the fact that he or she is constrained to live most of his or her life within the home.

Three of the 13 parental primary care givers who reside in Gozo specifically underline that the level of support available to them as well as to the son or daughter are somewhat restricted.

**Table 10: Concerns and Issues Raised**

<table>
<thead>
<tr>
<th>Assistance in taking care of the disabled person, general services and more care workers including payment (or benefits) for such services as it is difficult to manage the family and the disabled person at the same time or for the mother to enter into employment (16 times).</th>
</tr>
</thead>
<tbody>
<tr>
<td>More overall facilitation and support and financial benefits from Government: free services are very limited and this impacts quality of life of the family as a whole as support services are expensive or the family is unable to afford to provide the disabled person with the facilitation and support he or she deserves (14 times).</td>
</tr>
<tr>
<td>Need for a solution of who will take care of the disabled person when the parents become</td>
</tr>
</tbody>
</table>
frail and elderly or pass away (14 times).

Importance of measures to further integrate the disabled person with other persons through the provision of facilitation services as well as facilities he or she is able to attend as well as on-going extracurricular activities (14 times).

Increased opportunities for work (12 times).

Professional level of Learning Support Assistants should be improved and up-skilled (10 times).

Increased Learning Support Assistants service including payment for such services (8 times)

More need to educate the community on different disabilities so that a more engaging culture is inculcated (7 times).

Increased training in social skills and basic activities (money management, dressing, etc) to increase the disabled person’s independence (6 times).

Increased speech therapy including payment for such services – private sessions cost €25/hour (6 times).

Provision of training to parents to help them to understand and manage the disabled person better as well as to cope better (5 times).

CDAU services and support should be increased and more regular (5 times).

Increased occupational therapy including payment for such services (4 times).

Concern that Teachers do not understand or treat disabled persons well – such as ignoring the disabled person – as well as there is limited feedback between the parents and the Teacher and at times a lack of understanding from the School (4 times).

Concern that State’s commitment to disabled persons is to the age of 16 years – thereafter the family and the disabled person are left on their own and there is no specialised service that assures that the disabled person is provided with continued education (4 times).

Improved public access to facilities, and public transport as well as safe general facilities: safe parks, provision of seat belt, A/C in transport (4 times).

Need for increased independent living support services (4 times).

Schools should be better equipped to provide an accessible environment and an integrated environment for disabled persons (4 times).

No opportunities and proper support services in Gozo for disabled persons (3 times).

Always found assistance from KNPD (3 times).

School support is positive (3 times).

No respite services that allow parents to take a ‘break’ from the continued pressure and stress
of taking care of a disabled person (3 times).
Always found assistance from Agenzija Sapport (2 times).
Safety of certain facilities are not up to standard as they are shabby and in instances disabled persons are exposed to danger such as electric shocks (2 times).
Transport facilities to take disabled persons to and fro to supporting entities and environment for those parents or staff members who have no car or are unable to drive (2 times).
Access to Catechism services (1 time).
Disabled persons should be given the chance by employers to try (1 time).
Need for the introduction of a Trustee Framework that will allow parents to plan for the future of their son or daughter (1 time).
Concern that Nurseries are resulting in further damage to a disabled person (1 time).
Concern with regard to examinations and opportunities for higher education (1 time).
Persons may be labelled as having challenging behaviour and are subsequently stigmatised or associated as an illiterate person (1 time).
A Minister for Persons with Disabilities should be appointed (1 time).
Need for early one to one statementing of a disabled person upon being enrolled in an educational environment (1 time).
Concern that the disabled person will be bullied when he or she gets older (1 time).
State support environment is ‘tough’ as they segregate and prioritise and yet services provided are limited (1 time).
Abuse of disabled persons in institution (1 time).
Opportunities to go abroad with friends (1 time).
Professional and improved day services (1 time).
Not enough supportive policies from the State and KNPD (1 time).
Increased awareness to parent on support services and benefits available (1 time).
Increased opportunities to place disabled person in a care environment (1 time).
Role of parents taking care of a child with challenging behaviour is fraught with difficulties and there should be increased acknowledgement and support (1 time).
Increased educational activities – writing, colouring (1 time).
Assistance in handyman, home improvement services (1 time).
04.2 Staff Members Working with Disabled Persons with Challenging Behaviour

04.2.1 Age and Gender of Staff Members Working with Disabled Persons with Challenging Behaviour

The staff members within this sector were responsive to being interviewed and contributed with ease to the research process. Although the staff members describe situations and events that are unique in many ways, they all share similar beliefs, experiences and feelings concerning young children’s social and emotional development. Overall the staff members reiterated how they make an effort to treat all children fairly, and they encourage confidence in their disabled persons by providing an environment that is safe, loving, and nurturing.

Figure 38: Gender of Staff Members

As can be seen from Figure 38, the majority of the staff members, 88% are female and only 12% are male. The situation is also reflected in Gozo, where 11 of the staff members interviewed are female and 1 is male.
Figure 39: Gender of Staff Members who Work in Gozo

Forty six percent of the staff members are between 20 to 29 years. As can be seen, there seems to be an attrition in the level of staff members once they come into the age group of 30 years and over: standing at a relatively stable 16 – 17% for the age groups between 30 to 59 years with a nominal representation in the 60 years and over cohort.

Although a withdrawal from a career by a female staff member once she enters the 30 years and over age cohort reflects a national behaviour profile as statistics shows that female participation falls once a female moves into the 30s age group and over, the fall in employment from 46% to a stable 17% once the staff member is 30 years and over seems to suggest that staff members in this sector tend to opt out and potentially not return into the sector.

This may indicate that there is a potential burn out factor that compels a staff member to work out completely from the profession or migrate to other work in the sector.

Figure 40: Age of Staff Members
Figure 41 presents the age profile of staff members who work in Gozo. As can be seen, the 20 to 29 age group is highly represented – though there is a 50% representation of staff members in the 40 to 59 years group. This seems to indicate that there is a higher propensity for a staff member in Gozo to remain or return back to her profession given that 5 out of the 6 staff members in this age group are female.

Figure 41: Age and Gender of Staff Members who Work in Gozo

04.2.2 Qualifications and Specialist Training of Staff Members Working with Disabled Persons with Challenging Behaviour

The figure below presents an overview of the qualifications of the staff members interviewed in both Malta and Gozo. It is stated by staff members that one of the complexities is the balancing of the need for consistent standards within this profession as well as addressing the needs of all the disabled persons with challenging behaviour. The unifying principle of all the staff members interviewed is that to improve the quality of life of disabled people with Challenging Behaviour.
It is pertinent to underline that 55% of the staff members hold an undergraduate degree from the University of Malta. These degrees range from a Bachelor in Education, Degree in Nursing to a Degree in Communication Therapy. Additionally, 19 of the respondents hold a diploma from MCAST. Moreover, 3% of the interviewees hold a postgraduate degree specialising in an area of disability, such as a Masters in Autism.

There are, however, 23% who have not undergone any training within this sector. As can be seen from the Figure below the number of staff members amongst the female staff members who hold a formal qualification is 81.8% - whilst that of males is 58.33%.

Figures 44 to 47 show the education profile of staff members in Gozo. One of the staff members holds a post graduate degree (out of the 3 staff members who hold a post graduate qualification amongst the total population); 5 hold a degree; and 2 a diploma. Six of the staff
members who hold a degree and diploma are within the age group of 20 to 29 years (2 hold a degree and female; 1 a diploma and female) and 40 to 49 years (2 hold a degree and female; 1 a diploma and female) respectively.

Figures 44 to 46: Qualifications and Age of Staff Members who Work in Gozo

It is pertinent to note that of the 4 staff members (female) in Gozo who do not hold a degree, 2 are within the age group of 20 to 29 years and the remaining 2 in the 50 to 59 years of age cohort – which seems to infer that persons with no formal education in this sector are engaged despite that the access to training is far more available today.
Once in employment within the sector, 76% of the staff members undertook specialised training, which ranges from short courses to furthering their education with professional qualifications such as certificates in Inclusive Education. It is to be noted, however, that the 24% of the staff members did not avail themselves to continue their training.

It is pertinent to note, that there may be a mismatch between the expectations of staff members and of staff members who provide direct support to individuals in residences. The research seems to suggest that the latter may say that staff members do not understand the contrasting difficulties under which they work and produce advice that they may not be in a position to implement, whilst the former report that staff at times are unable to carry out necessary assessments and interventions.

The quality of staff support provided should, it is suggested, be focused on enabling the disabled person to engage in meaningful activity and relationships at home and in the community. Staff should be skilled and well-organised to deliver active support. Experience is certainly a contributor towards quality and below in Figure 48 one may note that most of the experience 54% of the staff members is between the range of 0 – 9 years.
The other facet of improving quality of service is the continuous professional development of staff. The figure below provides a breakdown of the staff members who underwent specialised training by age and gender.

**Figure 50: Specialist Training Received**

A good representation of the staff members in the age group of 20 to 29 years continue with a form of specialised training – that is 37 out of the total cohort of 46 staff members in this age group – or 80.4%
Similarly in the age cohort that is 30 to 59 years, the staff members who continue specialist training constitute 32 staff members out of a total of 49 – or 65%.

Moreover, 8 of the staff members who have continued with specialised training are male – which is 66.6% of the total male staff member population.

**Figure 51: Age and Gender of Staff Members Undertaking Specialist Training**

The staff members working in Gozo who continue with specialist training is only 50% of the total number of staff members who work there. Of note, however, is that 4 of the 6 staff members in Gozo who are in the age group of 20 to 29 years have carried out specialist training – which seems to positively indicate the younger generation of staff members in Gozo is more induced to continue with training and up-skilling.

**Figure 52: Staff Members who Work in Gozo who Undergo Specialist Training**
The staff members are likely to visit more than one institution. They may be based in hospital and then also visit the Institutional Care homes to provide their expertise. The below indicates the range in which the staff members worked.

<table>
<thead>
<tr>
<th>Figure 53: Caring Services provided</th>
<th>Figure 54: Caring Services Provided - Gozo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Others</td>
<td>Others</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Advocacy</td>
</tr>
<tr>
<td>Social and recreational support</td>
<td>Social and recreational support</td>
</tr>
<tr>
<td>Independent Support Living</td>
<td>Independent Support Living</td>
</tr>
<tr>
<td>Residential / Institutional Care</td>
<td>Residential / Institutional Care</td>
</tr>
<tr>
<td>Family Home</td>
<td>Family Home</td>
</tr>
<tr>
<td>Day Service</td>
<td>Day Service</td>
</tr>
<tr>
<td>Education / Training</td>
<td>Education / Training</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>Supported Employment</td>
</tr>
<tr>
<td>Open Employment</td>
<td>Open Employment</td>
</tr>
<tr>
<td>0 5 10 15 20 25 30 35</td>
<td>0 2 4 6 8 10</td>
</tr>
</tbody>
</table>

04.2.3 Staff Members’ Understanding of Challenging Behaviour

Staff members define challenging behaviour in various ways. Through attempts made during the research to engage interviewees to define the term ‘challenging behaviour’ it is noted that the staff members define challenging behaviour in terms of the behavioural characteristics, severities and effect on society.

In the main, the responses presented by staff members can be categorised under the following five definitions.

(1) “Describing challenging behaviour can be very difficult - it is very vast and complex – one has to consider the cause / what is behind the behaviour and beyond”.

(2) “Behaviour that does not fall within social norms”.

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Page 70
(3) “Moods in behaviour”.

(4) “Disturbed person who has no control and their behaviour need a lot of attention”.

(5) “Behaviour that can be very difficult to be included in the society through causing harm to others and the society”.

04.2.4 Impact of Training on Staff Members’ Ability to Work with Disabled Persons with challenging behaviour

The staff members feel that their training has prepared them to work with persons with challenging behaviour as may be noted below in Figure 52. 66% of the participants respond that the training has helped them ‘A Lot’. Twenty-two are classified between ‘Some and a Lot’ and ‘A Lot’.

Whilst only 1% indicate that they feel that the training received has prepared them to work with persons with challenging behaviour, it is still pertinent to state that 13% of the population surveyed is of the considered opinion that the training received is between ‘none at all and some’ benefit.

Figure 55: Affect of Training on Staff Members Ability to Work with Persons with Challenging Behaviour
If one had to segmentise the arising impact of training by age and category, it is to be noted that a significant number of staff members who say that the training has left ‘none or some impact are in the 20 to 29 years of age group – 8 or 17.4% of the 20-29 years of age cohort.

**Figure 56: Affect of Training on Staff Members Ability to Work with Persons with Challenging Behaviour: Between None at All and Some**

![Bar chart showing the impact of training by age and gender]

Even with regard to those that classified the impact of training on their ability to carry out the work as ‘Some’, the largest cohort of respondents also falls within the 20 to 29 years of age – and also, at 8 or 17.4% of the 20-29 years of age cohort.
Figure 57: Affect of Training on Staff Members Ability to Work with Persons with Challenging Behaviour: Some

The Figure below presents profile of those staff members who answered that the training has helped them positively with regard to the carrying out of their work.

As can be seen, 11 out of the 16, 12 out of 16 and 12 out of the 17 staff members who are in the age groups between 30 to 39, 40 to 49 and 50 to 59 years respectively answered positively – that is 71.4% of the said population.

On the other hand, only 27 out of the 46 staff members – or 58.7% - in the 20 to 29 years group classified the impact to be ‘A lot’.
With regard to the staff members who are employed in Gozo, 10 out of the 12 staff members in Gozo state that the impact of training on their ability to work is positive. The other 2 respondents state that the impact has been ‘some’ (male and within the 50 to 59 years of age group) and ‘between some and a lot’ (female and within the 50 to 59 years of age group).

Figure 59: Affect of Training on Gozitan Staff Members Ability to Work with Persons with Challenging Behaviour: A Lot
04.2.5 **Level of Confidence of Staff Members’ Ability to Work with Disabled Persons with challenging behaviour**

Given the high level of respondents who believe that the impact of training on their work is positive it is, perhaps, not surprising that the level of confidence felt by staff members in their ability to work with disabled persons with challenging behaviour is relatively high.

As can be seen from the Figure below, 71% of the respondents state that the level of confidence is ‘A Lot’ – of whom, 62 (or 70.4% of the female cohort) are female, and 9 (or 75% of the male cohort) are male.

Additionally, a further 18 staff members – 2 males and 16 females – respond that their level of confidence is ‘Between Some and A Lot’. Indeed, it is to be noted that the staff members who respond that they have a ‘Some’ level of confidence and below are 10 (1 male and 9 females) of whom only 1 classifies their level of confidence to be ‘None at All’.

**Figure 60:** **Level of Confidence of Staff Members Working with Persons with Challenging Behaviour**

It is interesting to note that the highest levels of confidence are felt by staff members in the 20 to 29 and the 50 to 59 years of age groups respectively.
Figure 61: Level of Confidence of Staff Members Working with Persons with Challenging Behaviour: Age, Gender and A Lot

The Figure below presents that segment of the population that responded that the level of confidence garnered is between ‘Some and A Lot’.

Those who answered that the level of confidence as ‘Some’, 3 are females in the age group of 20 to 29 years, and 4 are females in the age group of 30 to 39 years – with the remainder being in the age group of 40 to 59 years.

Once, again, the age group that attribute the level of confidence to this category is the 20 to 29 years group (7 persons) although here, too, it is of notice the respondents between the 30 to 59 years of age group.
The one respondent who expressed that the training has no impact on the level of confidence is a female and is within the 20 to 29 years of age group.

The staff members who work in Gozo ascribe their level of confidence as follows. Two females (one in the 20 to 29 and one in the 50 to 59 age groups respectively) state that their level of confidence is ‘A Lot’. The remaining 10 staff members define their level of confidence to be ‘Between Some and A Lot’. This is shown in the Figure below.

Figure 63: Level of Confidence of Gozitan Staff Members Working with Persons with Challenging Behaviour: Age, Gender and Between Some and A Lot’
04.2.6 Length of Experience of Staff Members Working with Disabled Persons with challenging behaviour

As can be seen from the Figure below, 11% of the staff members have an experience that ranges between 21 to 30 years.

**Figure 64: Age and Gender of Staff Members Working with Persons with Challenging Behaviour**

The majority of the staff members, however, (62) have an experience that is nine years or younger – which in turn reflects the observations made earlier with regard to the length of service in the profession by staff members.

Whilst this research has not specifically studied the correlation between ‘burn out’ and length of service it seems that there is a level of correlation between length and experience and the age of the staff members. It is suggested that further detailed research should be considered in this regard.

The staff members interviewed had in their responsibilities various disabled persons with several impairments, for example a disabled person could have autism and an intellectual impairment. The 100 staff members surveyed described the persons’ impairments and the disabled persons’ daily needs.
04.2.7 What Helps a Disabled Person Most

The great diversity and complexity of the group of behaviours subsumed by the term challenging behaviour, presents a number of challenges for the staff members who work with disabled persons with challenging behaviour.

The training should ensure that forms of support are appropriate to the diverse situations and circumstances of people with challenging behaviour and their families. In addition it should
also provide specialised support has access to specific skills and knowledge appropriate to the range of challenging behaviours.

Evidence from this research showed that staff members felt strongly about the four main ways proposed to handle disabled persons with challenging behaviour.

They feel rather strongly that spending time with disabled persons helps the person with their behaviour, 64% strongly agreed, whilst only 1% disagreed. They mention during their interviews that early intervention when signs are present that challenging behaviour may be about to occur is of paramount importance.

The aim here would be to diffuse the situation in order to prevent escalation of the behaviour and spending time with the disabled person would help to do so.

**Figure 67: Spending Time with Disabled Person Helps the Person to Deal with his or her Behaviour**

![Bar chart showing the percentage of staff members who agree or disagree with spending time with disabled persons helps to deal with their behaviour.](chart.png)

The Figure below shows the position on this matter with regard to staff members who work in Gozo. As can be seen, 7 – or 58% strongly agree.
Furthermore, the respondents indicated even more strongly that disabled persons were helped by calm behaviour and responses, a resounding 83% strongly agree. They believed that such a proactive approach would reduce the frequency, intensity or duration of the challenging behaviour.

The Figure below shows the position on this matter with regard to staff members who work in Gozo. As can be seen, 10 – or 83.3% strongly agree.
The response to if a disabled person is helped with better planning was also positive with a response of 76% stating that they strongly agree with such a statement and a 10% response to disagreeing to it. Changes in a person’s quality of life are both an intervention and a measure of the effectiveness of that intervention. Staff members believed that disabled persons were helped to take control of these daily events by the routines implemented through the planning of the daily care, and changes had to be positively implemented gradually.
The Figure below shows the position on this matter with regard to staff members who work in Gozo. As can be seen, 9 – or 75% strongly agree.

**Figure 72:** Disabled Persons Better Helped by Planning the Daily Care (Gozo)

A rather similar response was given when the staff members were asked if the disabled person reacted in a more positive manner when approached as an individual rather than a disabled person with 76% strongly agreeing and 12% disagreeing.

**Figure 73:** Better when Looked at as an Individual rather than a Disabled Person

The Figure below shows the position on this matter with regard to staff members who work in Gozo. As can be seen, 7 strongly agree.
Figure 74: Better when Looked at as an Individual rather than a Disabled Person (Gozo)

72% of the staff members interviewed strongly agree that disabled persons would be helped if they are taught new ways to respond. The strong disagreement to this approach was 14%.

Figure 75: Helped by Teaching the Disabled Person New Ways to Respond

The Figure below shows the position on this matter with regard to staff members who work in Gozo. As can be seen, 9 strongly agree.
Monitoring changes would indicate a change of pattern and help staff members to pre-empt behavioural changes in disabled persons, 73% of the staff members surveyed indicated that this would help whilst 9% disagreed.

The Figure below shows the position on this matter with regard to staff members who work in Gozo. As can be seen, 10 strongly agree.
The challenge of a particular disabled person’s behaviour for staff members and services is to find alternative ways of responding to the behaviour. Capacity and competence in the person’s environment are essential but the nature of the concept of challenging behaviour needs also other skills from the staff members.

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 the disabled person as an individual (76%), planning the daily care of the disabled person (76%), taking on a calm disposition towards the disabled person (83%) and spending time with the disabled person (64%) would be beneficially for disabled persons with challenging behaviour.
The Figure below shows the position on this matter with regard to staff members who work in Gozo.

The policies that staff members adopted depended upon the institution in which they worked and the stipulations under which they worked. Faced with a breakdown of an individual’s support and with limited resources, time and clear paths of access to a range of option staff members interviewed often have to adopt restrictive or custodial solutions of admission to hospital, and not adopting measures such as the above.
In addition, the staff members in this research cited their parents’ values and disciplinary styles as important influences on their approaches and responses to young children’s behaviour in the classroom and beyond.

This data also emerged when open ended questions were asked on what they perceived hindered inclusion. The points have been grouped and listed in descending order of importance, with the first one being the one most referred to.

1. Society - does not know how to deal and how able the disabled persons are. There is a stigma attached.

2. Parents being over protective.

3. Places not prepared to receive these disabled persons, lack of education.

4. Environment too stimulating, overcrowding.

5. No access for wheelchair users, for example ATMs, use of symbols easier than numbers for some disabled persons.

6. The condition they have needs supervision all the time. Even the same condition may have different symptoms.

7. Disabled persons themselves depending on the severity of the disability.

Therefore if in contrast one had to ask what would help, rather than hinder the inclusion of disabled persons with challenging behaviour, one staff member answered “the mentality of people in society to accept inclusion, preparation of what they are to come across, exposing the students to different situations”. This has to be done systematically as “Structure and planning beforehand needs to be there e.g. break down step by step how to make access to a service”. The points have been grouped and listed in descending order of importance, with the first one being the one most referred to.

1. More information.

3. Equipment, such as banking ATMs friendlier for disabled persons use.

4. A positive attitude by society towards disabled persons.

5. Inclusion in the community earlier on.

6. Parents who support the integration.
05. Observations

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.

05.1 Disabled persons

A number of observations that are to be taken into consideration in policy design with regard to persons who have challenging behaviour are noted. First, there is a concern, if not a fear, amongst parents to have their son or daughter to be labelled as a person with challenging behaviour.

The difficulty in reaching the appropriate 100 person sample and the statements expressed by parents 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 with regard to challenging behaviour so that such disabled persons are understood better and allowed to integrate further.

As important, the statement is 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 a person with challenging behaviour is “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 unclear whether this is the result of the fact that the extended family model may be stronger
to that in Malta or whether this is the result of an absence of facilities to support disabled persons generally.

It is to be noted that 3 (23.1%) of the parents of disabled persons who reside in Gozo remark that there are no supporting facilities in Gozo to which parents of disabled parents can turn to. It is argued, that the issue of whether parents of disabled children in Gozo find the necessary level of support in Gozo without the need to be doubly separated from the son or daughter through potential residential or institutional care in Malta merits study.

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 is made, repeatedly, that the fact that the disabled son or daughter with challenging behaviour 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.

It is to be noted that none of the respondents identified advocacy as an activity to which time is dedicated. As stated, only two disabled persons with challenging behaviour actually directly participated in this part of the survey. The impression that one gains in that more needs to be done to instil a culture of advocacy in this regard.

Whilst, the satisfaction level with regard to education services is primarily classified as ‘Positive’ a number of concerns raised by parents merit attention. The statement is made that frequent changes of a Learning Support Assistant assigned with a disabled student with challenging behaviour disrupts the person as well as the need to enhance the professional level of Learning Support Assistants with regard to the appropriate level of support they are to provide and on the condition of the disabled person they are working with.

Moreover, it is stated that Schools do not take time to understand a disabled child with challenging behaviour and does not provide the level of empathy as well as communication that the parents seek. The mentioned policy consideration to educate society should, perhaps, also be extended to schools and education authorities and professionals.
As shown in this research the majority of disabled persons surveyed are not in employment. One of the recurring issues raised by parents is the need for increased opportunities for work for persons with challenging behaviour. Whilst such a concern may not be limited to disabled persons with challenging behaviour, the lack of awareness as well as the potential stigma associated with this may render employers to be less likely to employ persons with challenging behaviour.

Finally, parents express a concern of what will happen to their son or daughter once they become too frail to take care of them or they pass away. Potentially this is not an issue that is limited to disabled persons with challenging behaviour but it denotes an urgent need for a policy solution given the fear that the care, love and support currently provided by the parents may not be there as they no longer are in a position to provide it.

05.02 Staff Members

This report has sought to present an understanding of the professional situation of the staff members working with disabled persons with challenging behaviour, and through such an understanding provide intelligence that will allow for appropriate policy design.

First of all, staff members should be monitored whereby a body whose responsibility to understand and develop the professional expertise of staff members within this sector visits various institutions and create common frameworks for them on policies such as how to behave with disabled persons with challenging behaviour.

This could lead to the development of training facilities for staff members which target specialised topics on challenging behaviour. Phrases such as “it was very frustrating” or “I didn’t know what to do,” indicated that the participants would benefit from in-service training or professional development in classroom management and had not had access to them.

Research needs to be conducted on how different policies are dealt with in sectors, for example, what are the policies on verbal/physical aggression. One researcher noted that the way that various institutions dealt with this was different, and then appropriate training implemented.
Secondly, the confidence of staff members at times was undermined by parents who did not follow their recommendations. A different form of support has to be available – both to educate parents about their children’s behaviour from a very early age and also with regards to the exit from the educational system. This would also mean pooling of existing resources so that hospital professionals gain more access to the disabled person at home and consequently influence parents. In fact, access to services was constantly a lament by parents, and the staff members felt that they had such a varied cohort of disabled persons that their expertise was often stretched. Therefore care has to be taken when implementing such an approach.

Thirdly, it is important that teacher education programs provide training in the practice of reflection. Staff members that come through the route of teacher training or psychology programmes are to be instructed on reflective teaching/training in order for them to be able to continuously develop their work practices within this sector. Also that support structures are in place for professionals working within the disability sector, such as schools, so that they are able to share their experiences and learn from each other.

The relatively high prevalence of different challenging behaviour, when combined with the great diversity and complexity of the group of behaviours subsumed by the term challenging behaviour presents a number of challenges for these staff members within the sector.

Disabled people with challenging behaviour feel generally disempowered and potentially are vulnerable to abuse or neglect. This in turn often means that they feel a lack of power to reduce their ability to challenge poor practice and restricts their access to redress. In order to support this group of people and their staff members a strong set of ethical standards and values is required. Both the staff members and the disabled persons need support to be able to focus on the individual needs which are so varied.

Fourthly, it is not clear from the research the extent to which an individual plan for the disabled person is prepared by the staff member. Although no specific question is presented in the questionnaire limited feedback comes out on the matter from the open ended questions.

Fifthly, it also seems that there is an under utilisation of effective behavioural methodologies. It could not be gauged from the questionnaire the extent to which staff members prepare
behavioural intervention programmes as the questionnaire did not specifically pose this question and limited feedback is presented from the open ended questions.

It is argued, that future research specifically direct questions to independently evaluate the quality and impact of such programmes, as well as the extent to which they are consistently followed as well as the short and possibly medium term reductions in challenging behaviour.

Sixthly, limited evidence emerges from the research that staff members, particularly with regard to disabled persons in institutions, apply physical restraint and seclusion to manage episodes of challenging behaviour who may show ‘more demanding’ forms of behaviour.
Appendix I: Consent Form

Research on behalf of KNPD with regards to Challenging Behaviour (part of project ESF3.105 Promoting the Social Inclusion of Disabled Persons with Challenging Behaviour)

KNPD issued a tender for the carrying out of research on disabled persons with challenging behaviour as part of its European Social Funded project Promoting the Social Inclusion of Disabled Persons with Challenging Behaviour (ESF3.105). The research is a first of its kind directed to obtain knowledge that will allow KNPD to design policy instruments as well as training and development programmes for persons with challenging behaviour as well as for primary-care givers and professional staff working with persons with challenging behaviour. The research targets two cohorts of research groups:

- Disabled persons with challenging behaviour or if this is not possible the interview will take place with his/her primary-care giver
- Professional persons working with persons with challenging behaviour.

I confirm that I have read and understood the questionnaire for this research study and I have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

I agree to take part in the above study.

I understand that the information gathered during the interview will remain anonymous and agree that it is stored in a specialist data centre.

Please initial box

Please tick box

Yes              No

I agree to the interview being audio recorded

I agree to the use of quotes which are anonymous in publications

Name of Participant                                       Date                                        Signature

Name of Researcher                                       Date                                        Signature

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

Investing in Your Future
Appendix II: Questionnaire for Disabled Persons with Challenging Behaviour or their Primary Care Givers

Question 01: What is the relationship between the Primary Care Giver and the disabled person with challenging behaviour?

Parent _______________________
Relative _______________________
Staff member ___________________
Others _________________________

Question 02: What locality does the disabled person come from

<table>
<thead>
<tr>
<th>Southern Harbour</th>
<th>Northern Harbour</th>
<th>South Eastern</th>
<th>Western</th>
<th>Northern</th>
<th>Gozo and Comino</th>
<th>Total</th>
</tr>
</thead>
</table>

Question 03: What is the impairment or condition of the disabled person

<table>
<thead>
<tr>
<th>Autism</th>
<th>Psychosis</th>
<th>Other mental Illness</th>
<th>Epilepsy</th>
<th>Mobility Impairment</th>
<th>Visual Impairment</th>
<th>Hearing Impairment</th>
<th>Dual Sensory Impairment</th>
<th>Intellectual Impairment</th>
<th>Others</th>
<th>Total</th>
</tr>
</thead>
</table>

Question 04: What are the daily activity needs of the disabled person

<table>
<thead>
<tr>
<th>Incontinent</th>
<th>Needs assistance with eating</th>
<th>Needs assistance with dressing</th>
<th>Needs assistance with washing</th>
<th>Restricted expressive communication</th>
<th>Restricted receptive communication</th>
<th>Going Out</th>
</tr>
</thead>
</table>

Question 05: Where does the disabled person live?

<table>
<thead>
<tr>
<th>Family Home</th>
<th>Residential / Supported</th>
</tr>
</thead>
</table>
**Question 06:** Where does the disabled person spend most of his or her time between 0700hrs and 2000hrs?

<table>
<thead>
<tr>
<th>Institutional Care</th>
<th>Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open Employment</td>
<td></td>
</tr>
<tr>
<td>Supported Employment</td>
<td></td>
</tr>
<tr>
<td>Sheltered Employment</td>
<td></td>
</tr>
<tr>
<td>Education / Training</td>
<td></td>
</tr>
<tr>
<td>Day Services (other than employment)</td>
<td></td>
</tr>
<tr>
<td>Family Home / Residential / Institutional Care / Supported Living</td>
<td></td>
</tr>
<tr>
<td>Social and Recreational</td>
<td></td>
</tr>
<tr>
<td>Advocacy</td>
<td></td>
</tr>
<tr>
<td>Other Forms of Support</td>
<td></td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
</tr>
</tbody>
</table>

**Question 07:** What is the overall satisfaction rating of the disabled person with regards to services provided

<table>
<thead>
<tr>
<th>Satisfaction Level</th>
<th>Positive</th>
<th>Mildly Positive</th>
<th>Mixed</th>
<th>Mildly negative</th>
<th>Negative</th>
<th>Unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supported Employment</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sheltered Employment</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Education / Training</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day Services (other than employment)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Home / Residential / Institutional Care / Supported Living</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social and Recreational</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Advocacy</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other Forms of Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others (specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Question 7a – Why do you rate your overall satisfaction as so? (reasons why the satisfaction rate is positive, mildly positive, mixed, mildly negative, negative)

__________________________________________________________________________________

Question 8: What type of challenging behaviour manifests itself:

<table>
<thead>
<tr>
<th>Aggression towards others:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal:</td>
</tr>
<tr>
<td>Physical:</td>
</tr>
<tr>
<td>Self-injury:</td>
</tr>
<tr>
<td>Mild</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>Severe</td>
</tr>
<tr>
<td>Frequency</td>
</tr>
</tbody>
</table>

Destructive behaviour

Other challenging behaviour

Question 9: What is the age and sex of the disabled person

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10-19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td></td>
<td></td>
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<tr>
<td>40-49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td></td>
<td></td>
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<tr>
<td>70+</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Question 10: Is there anything you wish to add

-----------------------------------------------------------------------------------------------
Appendix III: Questionnaire for Professionals working with Disabled Persons with Challenging Behaviour

Question 01: How long have you worked with disabled persons with challenging behaviour: 
____________________

Question 02: What is your job title: ________________________________

Question 03: Where do you provide your caring services:
Open Employment
Supported employment
Sheltered Employment
Education/ Training
Day Services
Family home
Residential/ Institutional Care
Independent Supported Living
Social and recreational support
Advocacy
Other forms of support

Question 04: How long have you been taking care of your current Disabled Person?
No of years: __________________________________

Question 05: What basic training have you undergone: ________________________________

Question 06: Have you ever had any additional or specialist training to supplement your basic training: Yes / No

Question 07: If the answer to the above is ‘Yes’ please list the additional training you have received (including any additional certificates, modules you have completed or training events you have attended)
________________________________________

Question 08: To what extent do you feel your basic training prepared you for working with persons with challenging behavior:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None at all</td>
<td></td>
<td></td>
<td>Some</td>
<td></td>
<td>A Lot</td>
</tr>
</tbody>
</table>

Page 99
Question 09: We are aware that sometimes different definitions are used to refer to persons with challenging behavior condition. Please provide a brief description of your understanding of the term ‘challenging behaviour’:


Question 10: How confident do you feel working with a disabled person with challenging behavior condition?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None at all</td>
<td>Some</td>
<td></td>
<td></td>
<td>A Lot</td>
</tr>
</tbody>
</table>

Question 11: What is the age and sex of your current Disabled Person?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10-19</td>
<td></td>
<td></td>
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<tr>
<td>20-29</td>
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<td>30-39</td>
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<td>40-49</td>
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<td>50-59</td>
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<tr>
<td>60-69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Question 12: What is the impairment of your current Disabled Person?

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td></td>
</tr>
<tr>
<td>Other mental Illness</td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td></td>
</tr>
<tr>
<td>Mobility Impairment</td>
<td></td>
</tr>
<tr>
<td>Visual Impairment</td>
<td></td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td></td>
</tr>
<tr>
<td>Dual Sensory Impairment</td>
<td></td>
</tr>
<tr>
<td>Intellectual Impairment</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td></td>
</tr>
</tbody>
</table>

Question 13: What are the daily activity needs of your current Disabled Person?

<table>
<thead>
<tr>
<th>Activity Need</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Incontinent</td>
<td></td>
</tr>
<tr>
<td>Needs assistance with eating</td>
<td></td>
</tr>
<tr>
<td>Needs assistance with dressing</td>
<td></td>
</tr>
<tr>
<td>Needs assistance with washing</td>
<td></td>
</tr>
<tr>
<td>Restricted expressive communication</td>
<td></td>
</tr>
<tr>
<td>Restricted receptive</td>
<td></td>
</tr>
</tbody>
</table>
**Question 14:** Do you find that the following helps:

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your spending time with him / him helps the person to deal with his behaviour.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is he / she helped by your use of calm behaviour and responses to his / her behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He / she is better helped by planning your daily care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He / she is better when the person is looked at as individual rather than a disabled person</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He / her can be helped by teaching the persons new ways to respond</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He / she can be helped by effectively monitoring changes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 15:** What do you think helps/facilitates the inclusion of disabled persons with challenging behaviour in accessing services?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

**Question 16:** What do you think hinders the inclusion of disabled persons with challenging behaviour in accessing services?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

**Question 17:** What is the age of the staff member: ____

**Question 18:** What is your gender of the staff member: M / F

**Question 19:** Is there anything you wish to add  
________________________________________________________________________