Policy and guidelines on working with disabled persons with challenging behaviour

Part of ESF3.105 ‘Promoting the social inclusion of disabled persons with challenging behaviour’
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The KNPD ESF3.105 Project
‘Promoting the social inclusion of disabled persons with challenging behaviour’

The Kummissjoni Nazzjonali Persuni b’Diżabilità (KNPD) is committed to rendering Maltese society an inclusive one, in a way that persons with disability reach their full potential in all aspects of life, enjoying a high quality of life thanks to equal opportunities.

This policy document has been produced as part of the ESF 3.105 project ‘Promoting the social inclusion of disabled persons with challenging behaviour’. The project is in line with the priorities of the National Sustainable Development Strategy mainly by addressing the goal of achieving progress which recognizes the needs of everyone and promoting social cohesion. It takes into account the particular needs of specific groups of disabled people to ensure that they are not excluded from society and that they do not continue to depend on intensive support services unnecessarily. By promoting their independence and self-development, services can become more sustainable and progress achieved in the disability sector can be truly enjoyed by all disabled people, including those with the most complex support needs.

The policy document was compiled by Outlook Coop Management and Communications. The document was written following a wide consultation exercise with the key stakeholders working in the field of challenging behaviour. A questionnaire, one to one interviews and focus groups were held with the stakeholders. Ms Charmaine Micallef and Mr Godfrey Kenely led the Outlook Coop team to carry out the consultation, research and writing of the document. The policy is intended for the sole use of the project. KNPD reserves its right to exclusive ownership of this report. No part of this publication shall be replicated and/or represented as an official version, nor as having been produced in affiliation with, or with the endorsement of, KNPD.
Definition: challenging behaviour

For the purposes of this report the term ‘challenging behaviour’ is defined as: “... behaviour(s) 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.”

Contents

Policy Rationale .................................................................................................................. 5
Policy Aims .......................................................................................................................... 7
Literature Review ................................................................................................................ 10
Person-centred planning: positive and structured behavioural plans ......................... 13
Staff: Recruitment, training and supervision ................................................................. 20
Developing a transdisciplinary approach ....................................................................... 23
Recommendations ............................................................................................................... 29
Components of values, theory, evidence and process ..................................................... 31
Training and supervision ................................................................................................. 32
Operational values ............................................................................................................. 33
The process of developing a person-centre, positive behaviour approach .................. 35
Transdisciplinary Team .................................................................................................... 35
Communication .................................................................................................................. 42
Conclusion ......................................................................................................................... 45
References .......................................................................................................................... 46
Policy Rationale

Family, carers and support people are often placed under great stress when faced by an individual’s, or individuals’, challenging behaviour. Challenging behaviour is often attributed to the person demonstrating the behaviour but the challenge often confronts everyone: the individuals, himself, or herself, family members or carers. This is because they might encounter difficulty understanding it or managing it. Furthermore, challenging behaviour is not often disassociated from the individual exhibiting the behaviour itself.

The Central Executive Committee of the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) remind us that the adoption of the term ‘challenging behaviour’ is to provide a reminder that the behaviour should be seen as a challenge to services. They state that a change in perspective in carers and family members, and an acceptance of difficulty in handling challenging behaviour is an important step forward. In this regard, the Council state that:

“It is our belief that there needs to be a firm reaffirmation of the term in its original context and a clear shift of emphasis back to the responsibilities for change being with the systems around the individual. We believe that ‘challenging behaviour’ is a socially constructed and dynamic concept. In order for an individual’s behaviour to be viewed as challenging, a judgment is made that this behaviour is dangerous ... distressing ... and that these feelings invoked in others are in some way ... overwhelming. The impact on others, and therefore the characteristics of the observer(s) have to be incorporated in the application and understanding of the term challenging behaviour.” (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007)

Challenging behaviour is therefore considered a product of an interaction between the individual and their environment. Intervention and service provision must therefore address the person, the environment and the interaction between the two.

To respond to this challenge, carers will be required to provide interventions that address inadequacies within the environment, inadequacies that do not address meet the individual’s needs. A comprehensive assessment should therefore be carried out to understand and address such inadequacies. This should include a functional assessment of behaviour, underlying medical and organic factors, psychological/psychiatric factors, communication and social/environmental factors. This assessment and diagnosis lead to a clear formulation of the presenting inadequacies. Following this, interventions can be made.

Interventions should be delivered in a person-centred context and in a framework of positive behavioural support. Such behavioural support should include proactive and reactive strategies which are thoroughly evaluated,
keeping in mind the needs of the individual as the primary focus. Services based on person-centred approach focus on the need to promote positive behavioural development which reduces the occurrence of challenging behaviour and maintain the individual’s access to a good quality of life despite continuing behavioural difficulties.

As focused in Valuing People: A new strategy for learning disability for the 21st century: A White Paper (2001), services must provide clear guidelines specifically focusing on person-centred approaches to planning services and support to improve “the lives of people with learning disabilities and their families and carers, based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent”.

Furthermore, in order for a comprehensive addressing and evaluation of the individual’s needs through a person-centred approach, communication and the timely sharing of information, common goal setting or feedback between professionals, carers and parents/guardians, is essential at all stages of care (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

The Council states that failure to work together, possibly through a transdisciplinary approach, has serious consequences on the quality of the service provided:

“It has been our historic failure to do that successfully that has resulted in people being excluded from mainstream society and segregated into inappropriate services” (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

Appropriate investment in training skilled professionals is a necessary component of change. However, it is not the sole component of change. A partnership between all people concerned with the lives of individual with challenging behaviour and a shared vision to end the exclusion from mainstream society of people is the only effective way forward toward strategic change.
Policy Aims

With this philosophy in mind, this policy aims at providing guidelines for strategic change for workers operating in the field of challenging behaviour. Firstly, the policy aims at reviewing key considerations raised in the consultation process. This will be done in the literature review. Secondly, the policy aims at providing operational guidelines aimed at stimulating strategic change.

In the UK, strategic change occurred after the publication of Facing the Challenge by the Kings Fund (Blunden & Allen, 1987), Meeting the Challenge (Allen, D., Banks, R. & Staite, S 1991) and the Mansell Report, Services For People With Learning Disabilities And Challenging Behaviour Or Mental Health Needs (Department of Health, 1993). These were reports which were instrumental in ushering in a change of perspective. The pivitol points of these reports are plainly visible in Appendix 4 of the Mansell Report (Department of Health, 1993) that lists key service objectives:

• “services will ensure that each person is treated as a full and valued member of their community, with the same rights as everyone else
• services will be individually tailored, flexible and responsive to changes in individual circumstances and delivered in the most appropriate local situation
• services will strive to enable people to live in ordinary homes and enjoy access to services and facilities provided for the general community
• services will be provided by appropriately trained, qualified and experienced staff who will help the people they serve to develop fully in all aspects of their lives
• services will be delivered in the least restrictive manner capable of responding to individual need
• services will strive to continually improve, using the latest research to provide the best treatment, care and support.”

As a result of this perspective and service objectives, the rights of individuals with challenging behaviour are enlisted as follows:

• the right to respect and dignity
• the right to live in and be part of the community
• the right to realize their individual capacities for physical, social, emotional and intellectual development
• the same right to access services to support a reasonable quality of life
• the right to choose their own lifestyle and to have access to information
• the right to participate in decisions which affect their lives
• the right to receive services in a manner which results in the least restriction of their rights and opportunities
• the right to pursue any grievance without fear of recrimination from service providers or discontinuation of services, and;
• the right to protection from neglect, abuse and exploitation.

With these service objectives and rights serving as the framework for the policy, the policy itself aims at introducing best practice guidelines for the carers working with disabled individuals exhibiting challenging behaviour.
It aims at understanding why an individual engages in that behaviour before attempting to understand how best to support the person. It therefore aimed at developing a better understanding and management of challenging behaviour.

Considering that challenging behaviour is often a message that conveys some sort of need, another aim is to provide guidelines indicating how best to understand the message. Following the understanding of, or function of, the message and individual's need, an evidence-based behaviour plan would have the primary goal of increasing a person’s quality of life and a secondary goal of decreasing the frequency and severity of their challenging behaviours.

In a bid to reach these aims, objectives are required. In the consultation process carried out with organizations in Malta and Gozo which work with individuals with disability with challenging behaviour, the following objectives have been echoed:

- developing an understanding of challenging behaviour
- developing a person-centred, positive, behaviour approach
- developing the skills and support strategies of staff members
- developing effective management based on positive organizational values
- developing a transdisciplinary approach
- developing an understanding of the role of communication
- developing consistency and equity in services in a joint effort to provide homogeneity and continuity of services.

The implications for services following these key objectives are:
- service planning and delivery should be highly individualized, to meet the widely differing needs of people in this group
- services should be planned on the basis of accurate information about individuals
- services should be designed and provided to reflect available research evidence about best practice
- the reduction of challenging behaviour is likely to require attention to other factors (such as communication) than just the behaviour itself
- assessing need should involve assessing service competence as much as individual characteristics.

(Mansell Report, 1993)

With the application of principles, the organization would:
- promote positive outcomes for the individual
- meet the individual needs and goals of the service user
- promote the inclusion of persons with disabilities
- maximize participation of the service user in community life
- ensure accountability on the part of stakeholders
- provide goal-directed service provision
- promote participation of the service user in the process of making decisions that affect their lives
- ensure that persons with disabilities have access to advocacy support where necessary to ensure adequate participation in decision-making about the services they receive
- ensure that the family is a stakeholder in decisions pertaining to the service user
- facilitate participation of the service user in the planning and operation of services and programs which they receive, and consultation on the development of major policy and program changes, and;
- respect the rights of the service user to privacy and confidentiality.
This policy document will draw upon the following UK policies:
- Mansell 2: Service for people with learning disability and challenging behaviour or mental health needs (2007)
- The Association for Supported Living (ASL): There is an Alternative (2011)
- RCSLT - Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings (2013)
- Royal College of Psychiatrists’ Faculty of Psychiatry of Intellectual Disability: People with learning disability and mental health, behavioural or forensic problems: the role of in-patient service (2013)

Within this policy document, the terms service user and service provider refer to the following:

**Service user** – a disabled individual with challenging behaviour whose specific social, psychological, physical needs are met within an organization that provides specific services or residential setting.

**Service provider** – an organization that provides services that addresses the social, psychological and/or physical of individuals with disability with challenging behaviour.
Literature Review

Challenging behaviour

‘Challenging behaviour’ is a term that has been widely adopted since its first introduction to the United Kingdom in 1987. This may be partly because of the ever-present drive to provide euphemisms for disturbing behaviours.

Emerson’s definition (1995), cited at the beginning of the document policy, has been quoted many times and has been recognized as definitive by many scholars of challenging behaviour. In 1996, Felce and Emerson further elaborated the original definition. They stated that one of the reasons for the adoption of the term ‘challenging behaviour’ was to provide a reminder that severely problematic behaviour should be seen as a challenge to services rather than an expression of psychopathological processes. “In order to respond to this challenge, services need to promote positive behavioural development, reduce the occurrence of challenging behaviour and maintain people’s access to a decent quality of life despite continuing behavioural difficulties” (Psychological interventions for severely challenging behaviours shown by people with learning disabilities: Clinical Practice Guidelines. The British Psychological Society, 2004).

The definition of challenging behaviour therefore, raises as many questions about the support services as it does about people with disabilities with challenging behaviour.
themselves. There is the concern that the people who challenge are not often seen in terms of their strengths, skills, development and quality of life as well as their challenging behaviour.

Any review of the literature on challenging behaviour demonstrates how broadly the term can be used. Many authors have dealt with the problem of definition by concentrating on a specific sub group of behaviours, such as self-injury, or aggression. Furthermore, studies indicate that a wide range of challenging behaviours often coexist (Clinical Practice Guidelines. The British Psychological Society, 2004).

In her survey of the incidence of challenging behaviour in the North West of England, Qureshi (1994) approached the definition of challenging behaviour in an operational way. She defined individuals as showing challenging behaviour if they:

- had at some time caused more than minor injuries to themselves or others or destroyed their immediate living or working environment; or
- shown behaviours at least once a week that placed them in physical danger, or caused damage and which required the intervention of more than one member of staff
- shown behaviours at least daily that caused more than a few minutes disruption.


This definition was revised in follow-up studies, when Emerson (1996) defined people with challenging behaviour as meeting at least one of these criteria:

- they showed challenging behaviour at least once a day;
- their challenging behaviour usually prevented the person from taking part in activities appropriate to their level of ability;
- their challenging behaviour usually led to major injury to either the person themselves, carers or other people with learning disabilities which in turn required physical intervention by one or more members of staff

(Clinical Practice Guidelines, 2004).

Other qualitative researchers have asked parents, or care staff, to identify what is challenging for them and worked from that basis, building up a shared understanding of what is challenging behaviour. Hastings, 1993 (cited in Clinical Practice Guidelines, 2004), showed that carers or staff he interviewed defined challenging behaviour in a variety of ways:

- challenging/difficult for others;
- not the norm/not acceptable;
- extreme reaction to ‘normal’ events;
- defined by examples;
- to be controlled/changed.

His work is important as he sheds light on how staff beliefs can affect their actions in reacting and working with challenging behaviours and that challenging behaviour is socially mediated.

In Transforming Care: supporting people with learning disabilities, autism and challenging behaviour to live happily in their local community (2014) challenging behaviour occurs as a result of a complex interaction between the individual and environmental factors. Individual factors are personal characteristics namely the severity of the disability, the presence of additional sensory, or motor, disabilities, communication difficulties, their personal history of relationships and experiences. Environmental factors are the characteristics of service namely the number, training and experience of staff, how they
work with the people they serve and with each other, the quality of the environment and the opportunities it presents.

In view of the fact that challenging behaviour can be considered as social construct, one understands that it is generally a response to adverse circumstances in the environment. As a result, service providers should create environmental conditions in which challenging behaviour generally decreases, particularly by improving the service user’s quality of life, by, for example, assisting him/her to develop new skills, gain self-confidence and experience choice. One realizes how important it is that service providers recognize the service user’s need for predictability, for sensitive and flexible provision in order to engage successfully in everyday activity and the need to exert control over how he/she lead their daily lives.

In sum, researchers have argued that an excessive focus on the challenging behaviour itself can divert attention away from important issues of how people with disabilities can be supported to live full and valued lives. Policy guidelines have indicated that priority must be given to helping people with disabilities who show challenging behaviours to learn new skills, reach their potential and participate in their communities. We would be doing these people a disservice if we did not address these issues which can become such a barrier to individual development and result in further social exclusion.

Furthermore, the complexity of the definition of challenging behaviour reflects the nature of work with people whose behaviour is challenging. The definition needs to be both tangible, so that the behaviours can be measured and worked with, and dynamic, so that the social and interactive elements are not lost. The use of the term ‘challenging’ to describe behaviours is an attempt to make this clear (Clinical Practice Guidelines, 2004).
Person-centred planning: positive and structured behavioural plans

The best starting assumption for understanding behavioural challenges is that behaviour is a form of communication. Individuals with challenging behaviour need to be heard and as a result, putting the individual at the centre of a service and providing person-centred approaches rather than the person being expected to fit into what the organization already does is the most important starting point for a service provider. This approach is core to the Putting People First (2009) agenda. The policy promotes the development of structured behavioural plans and subsequent service provided which are person-centred.

As reiterated in the NSW Manual, the development of a person-centred approach:

“...places the service user at the centre of service delivery, incorporating what can be learned about their lifestyle, skills, relationships, preferences, aspirations, and other significant characteristics, in order to provide appropriate, respectful, and meaningful behaviour support in a holistic framework. A focus on outcomes ensures that this support adequately addresses the changing needs of the service user.” Behaviour Support: Policy and Practice Manual Part 1 (A) Behaviour Support Policy (2009). NSW: Office of the Senior Practitioner, Ageing, Disability and Home Care. (pg 20).

The policy promotes the development of services which are person-centred and evidence and outcome-focused. This places the service user at centre of the behavioural support plan which is built on knowledge of the person including general skills, communication skills, likes and dislikes, needs and wants, relationships and other significant characteristics. Person-centred planning with outcomes as the main focus, directs all planning on the changing needs of the service user. Furthermore, a focus on
evidence ensures that it is the service centres around the needs of the service user and not that the service user centres around the services provided.

Person-centered planning focuses on individualization of programme, identifying and maximizing the strengths and preferences of an individual. Successful service is individualized in a number of ways. First, this recognizes that individuals require well-coordinated services, and that there is a commitment to meeting their users’ complex needs over the long term. Secondly, programme planning is based on thoroughly knowing and understanding the individual with specific outcomes for the individual such as independence, inclusion, choice and rights (Mansell, 1993). This can be achieved through assessment.

Assessment
To make an effective person-centred plan, a thorough assessment of the individual should be carried out. Assessment is the process of collecting and evaluating relevant information about the individual. Information should include intrapersonal factors, social, interpersonal and physical environment, as well as about the behaviour that is challenging (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

The purpose of assessment is to collect enough information to formulate a coherent intervention plan which fits the individual and his/her environment. The focus of the assessment should be determined by the impact of the behaviour on the individual and those around them, including the degree of physical harm to the individual and others. (Emerson 1995, cited in Emerson, 2001).

Another element to consider is the risk of loss of or limitation to access to opportunities for development and participation due to the levels of distress being experienced by the individual and others when challenging behaviour occurs.

Pre-assessment information should include several categories of information. These should include: descriptions of the challenging behaviour, circumstances in which the behaviour occurs, temporal statistics such as frequency as well as severity of the behaviour, the individual’s communication style, likes and dislikes, medical difficulty, current medication, setting in which the individual lives/works, previous interventions, existing risk management strategies (Sigafoons, Arthur, O’Reilly, 2003).

Assessing Risk
Risk is a fundamental aspect of behaviour that is described as challenging and its assessment should therefore be an integral part of all aspects of intervention and support (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007). Evaluation and description of risk should constitute a component of the assessment process and must be documented in the person-centred plan. The assessment should include a description of the behaviours including frequency, duration and intensity as well as an indication of who or what is at risk. The identification of these indicators should lead to early intervention aimed at providing behaviour support.

The NSW Behaviour Support: Policy and Practice Manual (2009) clearly delineates that there is a fundamental distinction between assessment and management of risk, and assessment of behaviour and provision of behaviour support. Therefore, risk assessment should not be used as an excuse to adopt a
'risk averse' stance that then severely restricts a person’s life further (Allen, 2002) but, on the other hand, risk assessment should be a tool to understand what behavioural support is required.

The Manual states that service providers have a “Duty of Care” towards the people who receive their service. The duty is to implement risk management strategies aimed at removing the risk of harm, or minimizing the harm, that may arise from daily activities or events in the user’s life, for example, nutrition, mobility, transitioning, etc. Additionally, documentation in such circumstances should detail what information was obtained to validate the harm-minimizing intervention, a projected timescale for the emergency measures and a clear indication of when and how a full assessment will be completed (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007). Moreover, harm minimizing interventions should in no manner pose a risk to loss of the various elements that make up quality of life, namely: rights, choice, independence, participation, inclusion (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

The NSW Manual (2009) states that:

“Risk evaluation and assessment should be pivotal components of a comprehensive behaviour assessment, and risk management strategies associated with an identified behaviour should be included in behaviour support plans.”

However, strategies developed only to manage an identified risk are not sufficient in themselves as they do not address the core issues namely the addressing of multiple needs of the service user’s life. A positive behaviour plan would be required to promote positive approaches, and deliver positive person-centred outcomes. In certain circumstances, however, an interim risk management strategy may be appropriate, for example in response to a crisis, or new challenging behaviour, or where a complete behaviour support plan has not yet been developed (NSW Manual, 2009). Nonetheless, any strategy used for the purposes of risk management should be viewed and used as a least restrictive alternative: no more restrictive or intrusive than is necessary to prevent foreseeable harm to the service user and/or others, and applied no longer than is necessary to manage an identified risk (NSW Manual, 2009).

Interventions
Following detailed assessment, intervention strategies should be clearer. Interventions should be delivered in a person-centred context and tailored to the individual, personal characteristics, environment and available resources for support.

Stakeholder involvement, such as professionals, in close partnership with families and other carers, should be a regular occurrence. Depending on the findings of the risk assessment above, interventions may need to take place in an environment in which safety and security can be offered (Mansell, 2010)

Whenever possible, interventions should be introduced one at a time in order to enable clearer evaluation of outcome. Within the positive behavioural support framework, the plan should include both proactive strategies for reducing the likelihood of the occurrence of the behaviour, and reactive plans for managing the behaviour when it does occur (Allen, James, Evans 2005) thus creating positive behaviour support. At the core of positive behaviour
support is recognition that reacting only to the occurrence of challenging behaviour, the use of ‘off the peg’ responses are counterproductive strategies. Positive behaviour support must include responses to a person’s challenging behaviour when it occurs (reactive strategy) and over time, what actions should be taken to reduce the need for the person to behave in ways which are less challenging (proactive strategies) (Transforming Care: Supporting people with learning disabilities, autism and challenging behaviour to live happily in their local community, 2014).

Proactive strategies address “the goodness of fit between the individual and their environment” (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007). Proactive strategies are characterized by “educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments” (Transforming Care, 2014). These strategies would be expected to reduce the frequency, intensity, or duration, of the challenging behaviour. This can be done either by attempting to address individual factors such as skills through systematic skills building, or addressing physical health problems or adjusting aspects of the environment in order that the environment itself are more supportive and less conducive to challenging behaviour.

These proactive strategies focus on:

- The quality and range of relationships and activities the person participates in
- The physical surroundings of the person and who he/she interacts with
- How predictable these factors are
- How staff and others communicate with the person
- How those who support the person manage occasions where there might be a risk of challenging behaviour occurring
- How other people might improve their understanding of the person and his/her behaviour.

(Transforming Care, 2014).

The LaVigna, Willis and Donnellan method (1989) delineates three categories of proactive strategies, (ecological changes, positive and proactive programming and focused support), and each of which makes its own contribution to a complex array of desired outcomes.

The method describes what proactive planning should follow and the different variations of positive-behaviour support programming. The first has the aim of increasing the person’s general skills and competencies across domestic, vocational and recreational domains. The second aspect of proactive positive programming teaches alternative behaviours (either communicative or otherwise) that are functionally equivalent to the challenging behaviour. The third teaches alternative behaviours that, while not equivalent, are functionally related to the behaviour we wish to decrease or eliminate. All three variations establish new behavioural repertoires that empower the individual either to influence the environment more competently or to get his or her needs met in a more socially acceptable manner. The fourth variation of proactive positive programming teaches the person to cope with and tolerate an environment that cannot be changed and/or one in which, at least for a time, his or her needs cannot be met.

Reactive strategies are designed to deal with the occurrence of challenging behaviour and specific incidents. This may involve early intervention when signs are present that challenging behaviour may be about to occur.
When one makes a parallel to the Arousal Chart, this stage would be identified with the Amber stage (Addison, 2013). The aim at this stage would be to diffuse the situation in order to prevent escalation of the behaviour. This will involve behavioural precursors that might indicate that the individual may be becoming agitated and likely to engage in challenging behaviour and identification of environmental triggers known to be associated with the behaviour. Should behaviour intensify to the reactive stage, physical management of the individual in order to ensure the safety of all those involved should be a last resort and thus a relatively rare occurrence and be in keeping with the relevant legal frameworks and principles of good practice.

The guide entitled: A Positive and Proactive Workforce: a guide to workforce development for commissioners and employers seeking to minimize the use of restrictive practices (2014) is concerned with developing workers so that they can work in a positive and proactive way to minimize the use of all forms of restrictive practices. This guide aims at reducing the need for restrictive interventions. The aims are based upon a number of shared key principles. These key principles underpin the need to deliver proactive care, which “requires rigorous governance in order to reduce excessive reliance on restrictive practices and interventions and to ensure that, when they have to be used, it is only ever as a last resort and is undertaken in a proportionate, least restrictive way” (A positive and proactive workforce, 2014).

Shared key principles are as follows:
• “compliance with the relevant rights in the European Convention on Human Rights at all times
• understanding people’s behaviour which allows their unique needs, aspirations, experiences and strengths to be recognized and their quality of life to be enhanced
• involvement and participation of people with care and support needs and their families, carers and advocates is essential, wherever practicable and subject to the person’s wishes and confidentiality obligations
• people must be treated with compassion, dignity and kindness
• social care and health service must support people to balance safety from harm with freedom of choice
• positive relationships between the people who deliver service and the people they support must be protected and preserved” (A positive and proactive workforce, 2014).

Restrictive Practices
Individuals with disability with challenging behaviour have the same rights and responsibilities as anyone else in the community. Where support strategies are used with the intention of influencing, or changing behaviour, these strategies must be sanctioned by means of a documented behaviour support plan which would have been created with the sole intention of promoting quality of life, upholding their dignity and safeguarding their rights.

In instances where restricted practices occur, a legal framework of operation should be in place. Additionally, the use of these restricted practices require prior consent requirement and can only be used within strict operational boundaries outlined in policy and law. Such a policy is the NSW policy (2009) in Australia. In this policy, the restrictive practices implemented are exclusionary time out, physical restraint, restricted access and seclusion. Strict adherence to policy guidelines is required when these measures are used.
Table 1: NSW policy, 2009

<table>
<thead>
<tr>
<th>Service User</th>
<th>Practice</th>
<th>Exclusionary Time Out (ETO), Physical Restraint Response Cost, Restricted Access</th>
<th>Seclusion</th>
<th>PRN Psychotropic medication</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children</strong></td>
<td>Parent or guardian</td>
<td>PROHIBITED</td>
<td>Parent or guardian</td>
<td></td>
</tr>
<tr>
<td>(under 18 years) not subject to court order reallocating parental responsibility</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td>Person with parental responsibility</td>
<td>PROHIBITED</td>
<td>Person with parental responsibility</td>
<td></td>
</tr>
<tr>
<td>(under 18 years) subject to court order reallocating parental responsibility</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Young people</strong></td>
<td>Guardian with a Restrictive Practices function</td>
<td>PROHIBITED</td>
<td>Either: (a) The Service User where they have the capacity; (b) The Person Responsible; or (c) The Guardianship Tribunal where the Service User objects</td>
<td></td>
</tr>
<tr>
<td>(16-18 years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Adults</strong> (18 years and over)</td>
<td>Guardian with a Restrictive Practices function</td>
<td>Guardian with a Restrictive Practices function</td>
<td>Either: (a) The Service User where they have the capacity; (b) The Person Responsible; or (c) The Guardianship Tribunal where the Service User objects</td>
<td></td>
</tr>
</tbody>
</table>

Furthermore, when restrictive practices are used as a component of a behaviour plan, these practices should be documented and the document should include:

- description of the proposed practice/strategy
- expected outcomes related to the proposed practice/strategy
- rationale for the use of the proposed practice/strategy, i.e., an explanation as to why positive practices alone are unable to achieve the desired outcomes
• roles and responsibilities, contextual variables, proposed frequency of use, event monitoring requirements, reporting protocols associated with the proposed practice/strategy
• formal data collection procedures for the proposed strategy

(NSW policy, 2009)

Also the following should be considered and documented:
• date, time and location of each episode of implementation
• brief description of environment and events prior to implementation of strategy
• description of presenting behaviour
• detail of other less restrictive strategies attempted (if any)
• consequences/outcomes of less restrictive strategies attempted
• reason for use of strategy
• duration
• the people involved in implementation of the strategy
• name and position of staff directing use of strategy and
• consequences/outcomes.

(NSW policy, 2009)

In view of the above, with a lack of legal framework on the specific (as is the situation locally in Malta), restricted practices may provide a serious infringement of rights and restraint to the dignity of the persons with disability with challenging behaviour.

(NSW policy, 2009)

Evaluation of Behavioural Support Plan
Carers are “under an ethical obligation to measure the impact of their interventions on the target behaviour, because the nature of challenging behaviour is such that, by definition, there is a threat to the health and well-being of the individual concerned or those close to him, or her” (Royal College of Psychiatrists, 2007). Hence, all interventions should be routinely evaluated for their effectiveness. Furthermore, this evaluation should be planned and dated at the point of initiation of the intervention. There is evidence to suggest that those interventions that are more thoroughly evaluated are more likely to demonstrate a positive outcome (Scotti 1991; cited in Royal College of Psychiatrists, Challenging Behaviour: a unified approach, 2007).

An evaluation will usually repeat baseline measures from the start of an intervention and look for any evidence of change. The measurement of challenging behaviour alone is an inappropriately narrow focus and as a minimum, the evaluation should consider:
• the severity, frequency and duration of the target challenging behaviour
• the individual’s quality of life and range of activities or opportunities
• the individual’s development of skills
• the individual’s well-being and satisfaction with the intervention
• the well-being and satisfaction of carers or family members in close contact with the individual.

Adverse effects of the intervention should also be carefully monitored. (Royal College of Psychiatrists, Challenging behaviour, 2007).
Staff: Recruitment, training and supervision

Working with people who challenge services and carers requires particular expertise and particular qualities. “Expecting people who present the greatest challenges to be supported by any standard staff structure and/or staff who have not been effectively trained and supported will almost certainly result in the service not being effective.” (Supporting Staff Working With People Who Challenge Services: guidance for employers, 2013).

The challenge is to ensure that there is the right level of expertise within the service whilst also ensuring that staff has access to additional expertise in the form of supervision and other assistance. Additionally managers also need to exercise ownership and understanding of the task of supporting front liners as well as individuals who challenge services, in order to maintain the quality of the support.

The Guidance for Employers Handbook (2013) makes some recommendations in order to maintain the level of service and support thus ensuring additional expertise within the service – both at a management level, to oversee quality and interventions, and at the service provision level, for day to day practice. They recommend that:

• core training programmes need to be established, using external trainers if needed, to ensure key staff are aware of and possess the skills and competencies needed
• services take a multi-agency approach to ensure cross fertilization of skills and expertise
• services set up mentoring for new members of staff with more experienced colleagues as part of the induction process
• services should consider the use of coaching for individuals who need specific skills. This may involve the use of external coaches or training staff to be coaches themselves.

Clearly, it is vital that the right staff is recruited to support people with challenging behaviour. A person-centred approach specifies personalization which indicates that staff should have skill and knowledge of best approaches to do that.

The Guidance for Employers Handbook (2013) offers some suggestions on practices that should be put into place when an agency recruits:

• Develop interest specifications tailored for individual people. Employers seek to match the interests of the service users to those of the staff recruited to support them.
• Look beyond qualifications and consider personal qualities such as listening skills. This can be achieved by using role specific personality tools to identify the right people, or develop teamwork tests that can be given at interview stage to demonstrate candidates’ values.
• Have rigorous, but flexible approaches to recruitment. For instance, employers might offer trials prior to appointment.
• Aim for diversity reaching more people of different ages and both genders.
• Discuss behaviour that challenges and its function as a possible communication tool during the recruitment process to establish the nature of the work early on.
• Where possible involve users being supported, their families and other carers in the entire recruitment cycle, in meaningful ways that they are comfortable with e.g. writing job descriptions, sitting on interview panels.
• Be clear with applicants at selection stage about the person centred culture of the service.
• Ensure effective induction that enables people to realize from the outset what the work entails.
• Ensure that safeguarding and whistle blowing policies and channels are understood and available to people right from the start.

It is important to ensure continuity of good staff in a service. The loss of important relationships with staff can create anxiety in an individual’s life. Whilst many advocate staff rotation as good practice for supporting some groups, consistency of staff is needed for individuals with challenging behaviour, and so this may not be the best approach to take (Supporting Staff Working With People Who Challenge Services: guidance for employers 2013).

It is understandable that working with people with challenging behaviour may create burnout in carers. For this reason, supervision is of utmost importance. From the services’ perspective, having staff leave is primarily disruptive to the service provided, as well as costly, since new staff must be recruited and trained. So it is in everyone’s interest to promote appropriate staff retention. However, there are also benefits when ‘new blood’ is allowed to infuse the services (Supporting Staff Working With People Who Challenge Services: Guidance for employers 2013). For instance, new staff may question the efficiency of existing work practices and help to address some long outstanding issues.

In order to design a workforce with very well developed knowledge and skills to support people with challenging behaviour, an employer needs to ensure that their service offers processes and systems which enable staff to use their skills effectively. Training must be at the very core of these systems. Effective professional training emphasizes the importance of training all staff on technical and non-technical matters and training them all together as a team. Training should be specially designed in-service training, reflecting the need of service. (Psychological interventions for severely challenging behaviours shown by people with learning disabilities: Clinical Practice Guidelines. The British Psychological Society, 2004).

**Investment in relationships**
Training staff to a high degree of skill will not, on its own, lead to high quality support (Institute for Public Care, 2012). This is because services should not only provide technical support related to provision of treatment and care but also emotional support of staff. While technical support is largely provided through professional staff, psychological support, in recognition of the heavy demands that working with people who present challenging behaviour make on staff, is equally important (Mansell, 1993).

Service providers need to have the structure and culture of supervision and psychological support for staff in place to support the application of skills (Institute for Public Care, 2012 cited in A positive and proactive workforce: A Guide To Workforce Development For Commissioners And Employers Seeking To Minimize The Use Of Restrictive Practices In Social Care And Health: Department of Health, 2014). Members of staff conducting assessments, planning and consulting on behaviour support should be receiving regular practice support from an appropriately qualified and skilled supervisor. It is the role of the supervisor to monitor implementation
of behaviour support strategies, promote consistency in their implementation and address performance issues (Institute for Public Care, 2012).

For individual service users, a history of challenging behaviour is also, and often a history of discontinuity in relationships and of bad experiences in relating to other people (A Positive And Proactive Workforce: A Guide To Workforce Development For Commissioners And Employers Seeking To Minimize The Use Of Restrictive Practices, 2014). Hence, an effective service invests heavily in terms of technical training and supervision as well as non-technical support of staff, namely psychological support.

Management
Good management is crucial in ensuring that professional specialists and front-line staff work together, that specialist advice is available, practicable and sensible and that staff follow the advice provided (Mansell, 1993). Furthermore, since virtually all service providers claim to provide individualized care based on the assessment, it is essential that service managers can really discriminate between what constitutes good practice and what does not. It is important, therefore, to look directly at the lives of the individuals in their care and, for instance, evaluate how they spend their time, how much help they get from staff, what relationships they have with staff (Behaviour Support: Policy and Practice Manual Part 1 (A) Behaviour Support Policy, 2009).

Organizational values
Structures and culture operate from values set by the service providers. Values in a service are important as they provide direction to the way that service are organized, managed and delivered. Service would need to operate within a culture that operates from these values:
• to recognize that the person is central to the service it delivers
• to operate in a culture of openness, respect and transparency, and
• to have service leadership which is fully committed to promoting person-centred programmes and minimizing the use of restrictive practices
  (The British Psychological Society, 2004).

Service providers would need to have management teams that need to be in touch with what actually happens within the service. They would need to have systems in place to develop a culture of learning from practice, sharing and promoting good practice with a proactive response to poor practice (Institute for Public Care, 2012 cited in A positive and proactive workforce, 2014).
Developing a transdisciplinary approach

It is a common recommendation that a transdisciplinary model would be considered. The transdisciplinary approach has been recognized as best practice for early intervention (Bruder, 2000; Guralnick, 2001 cited in King, G., Strachan D., Tucker, M., Duwyn, B., Desserud, S., Shillington, M., (2009), and many early intervention programmes adopt this approach (Berman, Miller, Rosen, & Bicchieri, 2000 cited in King, G. et al (2009).

A transdisciplinary team is one in which members come together, share their individual expertise, jointly communicate, exchange ideas and work together. The primary purpose of this approach is to provide more coordinated and integrated service to meet the needs of the individual with disabilities (Carpenter, 2005). Transdisciplinary models of practice aim to integrate the expertise of team members so that more efficient and comprehensive assessment and intervention service may be provided. In contrast to other service delivery approaches, the transdisciplinary approach is considered to reduce fragmentation in services, reduce the likelihood of conflicting approach and enhance service coordination (Carpenter, 2005; Davies, 2007 cited in King, G. et al (2009).

A transdisciplinary model differs from a multidisciplinary approach. The former approach transcends discipline-specific roles. The latter makes use of different disciplines at once but does not bridge disciplines (King, Strachan, Tucker, Duwyn, Desserud, Shillington, 2009). The communication style in a transdisciplinary team involves continuous give-and-take between all members on a regular, planned basis. Professionals from different disciplines teach, learn, and work together to accomplish a common set of intervention goals (King et al 2009). In the transdisciplinary model, assessment, intervention, and evaluation are carried out jointly by designated members of the team.

The key difference in approaches is that the transdisciplinary model role differentiation between disciplines is defined by the needs of the individual rather than by discipline-specific characteristics characterized by the multidisciplinary model.

“Transdisciplinary service is defined as the sharing of roles across disciplinary boundaries so that communication, interaction, and cooperation are maximized among team members (Davies, 2007 cited in King, G. et al (2009).” The approach is characterized by the commitment of its team members to work together to implement coordinated service and develop a shared vision (Fewell, 1983; Peterson, 1987; United Cerebral Palsy National Collaborative Infant Project, 1976 cited in King, G. et al (2009).

Amongst the benefits of a transdisciplinary approach, one considered the efficiency of the service as this model offers a one stop shop model in which the client is considered holistically. Interventions are coherent and collaborative, facilitating less intrusion for the family and client him/herself. An added benefit is the facilitation of professional development

A transdisciplinary approach has three essential operational features, as follows:

1. The arena assessment: professionals from multiple disciplines assess the individual simultaneously, using both standardized measures and informal methods (Foley, 1990). A brief discussion of information and impressions are discussed once the assessments are completed while a more definitive formulation is made once the team has had time to analyze the data and reflect upon its findings.

2. It is a collaborative inter-professional team engaged in intensive, ongoing interaction among team members from different disciplines, enabling them to pool and exchange information, knowledge, and skills, and work together cooperatively (Foley, 1990)

3. Role release: the team members “release” intervention strategies from their disciplines. The role release process involves sharing of expertise in an environment where perspectives, knowledge, and skills of those from other disciplines are valued and trusted.

One published practice evidence-based transdisciplinary model of early intervention service is called “Team Around the Child” (Davies, 2007 cited in King, G. et al (2009), based on work by Limbrick 2005, cited in King, G. et al (2009). In the UK, Davies outlines ten (10) model components for transdisciplinary intervention, some of which include: philosophy, family role, key worker role, team interaction, lines of communication, staff development, and the assessment process. These model components will be highlighted in a service model example named the Home Visiting Program for Infants (HVPI) which has operated a transdisciplinary programme for the past 30 years (King et al, 2009). A view of this model will translate the rhetoric of the transdisciplinary approach into reality.

HVPI is an early intervention programme to enhance the growth and development of infants and young children younger than 6 years of age who have developmental disabilities. The programme provides service coordination of assessment, treatment, and consultation service for each child as well as family support and education.

Each family is assigned a primary therapist, or professional, who may, for instance, be an occupational therapist, physiotherapist, or speech-language pathologist. The primary therapist is the key contact person between the family and the rest of the professionals. S/he is responsible for developing a therapeutic relationship with the family; offering emotional support, building advocacy skills and providing information on issues related to health, development, treatment options, and community resources. It is his/her role to facilitate communication between parents and team and implement the plan of care (King et al 2009).

The primary professional does not exclusively deliver all service to the family. Even though the family may see one professional most frequently, every family is supported by the larger team. Arena assessments, consultation services, short-term therapy, and groups are examples of ways that team members other than the primary therapist provide direct service to families. Indirect support is provided to the family via the primary professional, who regularly confers with other team members, both formally and informally (King et al 2009).
During the HVPI arena assessment, families are offered the opportunity to take part in an arena assessment. Prior to the assessment, the primary professional speaks with the family about their aims and then conveys the parents’ goals for the assessment with the team. The assessment team typically consists of a psychologist, an occupational therapist, physiotherapist, social worker, and speech-language pathologist. Following the assessment, the team meets with the family to discuss their priorities and concerns, outline next steps, and answer specific questions the family may have. During the arena assessment process, parents meet team members face-to-face and ask them questions specific to their disciplines. The team then engages in a debriefing process, intended to support the primary professional and this process provides opportunities for team members to provide feedback to one another. The primary professional then develops an intervention plan based on the assessment information and family priorities, and implements the plan while other team members monitor implementation and provide role support as needed (King et al 2009).

The arena assessment as used by HVPI is beneficial because it meets family needs making them main stakeholders in the ideation and provision of the support plan. Furthermore, service providers have “personal responsibility to engage in role extension, enrichment, and expansion through self-directed study, dialogue and interaction with other team members, and self-appraisal and reflection. An attitude of openness to learning will enable them to embrace learning on the job” (King et al, 2009).

Hence, this particular transdisciplinary model develops the skills necessary for collaborative inter-professional teamwork such as include listening and communication skills, negotiation skills, skills in giving and providing feedback, and skills in resolving conflicts and reaching consensus (King, Batorowicz, & Shepherd, 2008). It is a model that enhances the practice of professional development and a supportive, learning-based environment which enhances personal responsibility for professional development.

**Communication**

“Communication is a two-way process. Communication refers not only to the communicative skills of the service user, but also to those of others in the support system, particularly carers. For people with an intellectual disability and complex communication needs, it is crucial that all parties in the support system are able to communicate appropriately and effectively. This will usually require the design and consistent implementation of a formal communication system.” (Behaviour Support: Policy and Practice Manual Part 1 (A) Behaviour Support Policy, 2009).

There is recognition of the growing evidence supporting a significant link between communication difficulties and challenging behaviour (NSW Manual, 2009). Communication is a significant risk factor contributing challenging behaviour. This is because:

- up to 90% of people with learning disabilities have communication difficulties.
- around half have significant difficulties with both expressing themselves and understanding what others say.
- only 5 -10% of people with learning disabilities have recognized literacy skills and most are not be able to access standard written information.
- the incidence of additional sensory impairments, including sight and hearing,
is much greater than in the general population. Up to 40% of people with learning disabilities having a hearing loss that is often missed or undiagnosed.
(Royal College of Speech and Language Therapists. Five good communication standards, 2013).

Furthermore, without good communication people may be at risk of experiencing:
• a lack of choices and involvement in everyday decisions
• limited relationships
• increased vulnerability to abuse
• low mood, anxiety and depression, and withdrawal from community life

Due to this evidence, comprehensive assessment of behaviour should be informed by a detailed and recent assessment of the service user’s communication skills. Where no recent communication assessment has been completed, the behaviour support plan should proceed on the basis that any strategies developed are subject to review when the communication assessment report has been completed.

There are a number of communication-focused interventions and approaches to challenging behaviour which have been reported in the literature (Bradshaw, 1998; Brown, 1998; Chatterton, 1998; Dobson et al, 1999; Thurman, 2001 cited in The Central Executive Committee, 2007). These have typically attempted to improve the communication skills of the individual with challenging behaviour and/or their communication partners and environments. This may include interventions designed to increase the communication skills of the individual, for example increasing the effectiveness of existing communication skills, an example of which would be increasing the clarity of communication as well as teaching the individual more ways of communicating, such as teaching vocabulary, or forms of communication as signs, or symbols. The skills of the communication partners may also be enhanced. For example an individual’s communication skills may be recognized more clearly, improving communication interchange and understanding and expression. This in turn might assist communication partners to provide appropriate models of communication facilitating communication partners’ use of appropriate forms of communication, such as use of signs, symbols and objects, in addition to spoken communication structuring partner communication so that it is within the individual’s understanding and the wider communication environment (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007). For example, listening environments could be promoted e.g. by reducing distractions and background noise or opportunities for taking part in a range of communication may be provided e.g. to ask questions, comment, etc.

Communication-based interventions may also be challenging behaviour-specific, such as interventions found within the literature related to functional communication training (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007). Once the functions of behaviours have been assessed, attempts are then made to replace these behaviours with a functionally equivalent communicative response. For example, teaching the person to use a Makaton sign for ‘break’ to replace behaviour that serves the function of avoiding demands. Such interventions have been shown to reduce the level of behaviours that are challenging (Carr & Durand 1985; Carr et al 1991; Durand & Carr,
Communication interventions within the support plan must be evaluated. For instance, where Augmentative and Alternative Communication (AAC) Systems have been developed in support of an individual, careful analysis should be made not only on the service user’s ability to use the AAC System, but also on the competency of the carers to use the same AAC System effectively. Furthermore, AAC systems should be developed in response to assessed communication preferences and skills of the Service user. For instance, the communication system may take the form of auditory modalities such as verbal cues or the spoken word. The system may be designed for operation using low-tech modalities such as visual timetables or access cards, or using high-tech modalities such as microcomputers and software packages.

The Royal College of Speech and Language Therapists (2013) issued a report that identifies outcomes for individuals with a disability with behaviours described as challenging, who live in specialist hospital and residential settings. These include:
- being safe
- being treated with compassion, dignity and respect
- being involved in decisions about their care
- knowing those around them and looking after them are well supported
- making choices in their daily life
- receiving good quality general health care

The report also states that good communication underpins all these outcomes. Most people with disabilities with challenging behaviour have some speech, language and communication difficulties which can be hidden or overlooked (Royal College of Speech and Language Therapists, 2013). Implementing good communication is proactive and prevents reactive interventions. The policy states that failure to make reasonable adjustments to meet communication needs would increase vulnerability to a range of risks.

The Royal College of Speech and Language Therapists (2013) recommends five good communication standards within a service setting. The aim for these standards is to ensure that reasonable adjustments are made to meet the speech, language and communication needs of individuals with disabilities or autism in specialist hospital and residential settings. These standards are drawn together using practitioner knowledge from expert speech and language therapists across England, Scotland and Wales.

The five good communication standards are intended as a practical resource to support families, carers, staff and professionals to make a difference to the lives of individuals using specialist residential services. As a result of these standards, all stakeholders should be able to know:
- What good communication looks like
- Whether good communication is happening
- About useful resources to promote good communication

The five good communication standards are as follows:
Standard 1: There is a detailed description of how best to communicate with individuals.

Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.
Standard 3: Staff value and use competently the best approaches to communication with each individual they support.

Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate.

Standard 5: Individuals are supported to understand and express their needs in relation to their health and wellbeing.

(Royal College of Speech and Language Therapists, 2013).

The individual risk of having a communication difficulty means individuals are misunderstood, experience exclusion from community activities and relationships. However, communication is also an environmental risk factor. Evidence shows staff do not generally interact with the people they support in a way that enables individuals to achieve greater levels of independence, participation or integration (Royal College of Speech and Language Therapists, 2013). This indicates that providers of specialist residential service need to develop their expertise to provide meaningful interaction and good communication environments. Staff need the skills to make reasonable adjustments to maximize engagement, involvement and inclusion. Good communication thus enables inclusive relationships, supporting individuals to have choice, control and greater independence. Good communication only exists as part of positive everyday relationships, boosting self-esteem and success. Good communication crosses all dimensions of care, support and enablement. Without good communication individuals struggle to learn, achieve and interact – all fundamental for to improving quality of life.
Recommendations

In 2012, a survey was presented entitled *The Current Situation Of Disabled Persons With Challenging Behaviour In Malta: promoting the social inclusion of disabled persons with challenging behaviour* (KNPD: Executive Summary, 2012). This survey was carried out as part of the ESF co-financed project Promoting the social inclusion of disabled persons with challenging behaviour. Observations from parents and members were recorded.

With respect to parents, three major observations were noted:

1. There was a concern amongst parents to have their son or daughter labeled as a person with challenging behaviour. Because of this, it was difficult to reach data sampling numbers. This indicated fear of stigmatization. Particular parents felt the need for general awareness and education of society and specific entities such as local schools who somewhat provide for people who challenge, in a bid for better inclusion. Furthermore, parents themselves felt the need to be trained to better understand why their son/daughter exhibits challenging behaviour as well as be afforded the appropriate support in terms of care and respite.

2. Parents of disabled persons in Gozo stated that, due to lack of good provision and respite, there are no support facilities in Gozo to which parents can turn to.

3. Parents felt the absence of support frameworks that assist parents as well as disabled persons with regard to social and recreational, as well as ongoing extracurricular, activities. This resulted in restrictions imposed on the disabled individuals at his/her place of residence for long periods of times which might be an important variable to increase the level of frustration and, potentially, accentuate challenging behaviour.

With regard to staff members, three major observations were noted:

1. Carers felt a need for the development of training facilities for those working with persons who challenge.

2. It was proposed that there should be a pooling of existing resources.

3. It was proposed that there is a need for a training programme that provides training in the practice of reflection in order for them to be able to continuously develop their work practices.

Following the survey, training was given to carers working in the field. These have been followed up by supervision and participant assessment. The participants further disseminated the information by giving courses to fellow staff members. Hence, some objectives of the survey had been reached, however some lacunae were still felt.

In order to feel the current pulse of service provision in Malta as well as to identify such lacunae in this field, consultation with key stakeholders operating in the field was held. As part of the consultation process, questionnaires regarding practice and identification of needs were sent to fifteen organizations, in Malta...
and Gozo, working with people with disability with challenging behaviour. A compendium of the services provided by these organisations is available from www.knpd.org. Furthermore, one to one interviews were held with members of these organizations. Following that, three focus groups were held to present findings of questionnaires and interviews as well as review relevant literature. The focus groups served also to collect suggestions for policy recommendations.

Recommendations and guidelines for the policy have been identified after this consultation process. These recommendations and guidelines are aimed at providing guidelines of operation for the management and carers who provide services for service users with behaviour that challenge the services. The ultimate aim is that good proactive workforce will contribute by giving higher quality service, providing better outcomes for people using the services.

Findings from the review and participants view on policy content are as follows:
• developing a person-centre, positive behaviour approach
• developing skills and support of staff
• developing effective management based on positive organizational values
• developing a transdisciplinary approach
• developing an understanding of the role of communication
• developing consistency and equity in services in a joint effort to provide homogeneity and continuity of services

Specifically, with respect to front line workers, carers should:
• feel knowledgeable, skilled, competent, and supported in their job to the best of their abilities
• know standards of operation and what is expected of them

From the managerial point of view, management should:
• feel confident and assured that they are developing workforce to deliver a quality service
• feel aided in creating an environment of good staff recruitment and retention
• provide evidence for good standards of operation

During the consultation process, other issues were raised by the focus groups. These are listed below and should certainly be considered for future focus:
• audit of services and staff operating in the field
• networking of human resources
• creating awareness at a national level
• further training to LSAs, mainstream teachers
• parental training and support
• curriculum differentiation
• community inclusion projects

The main guidelines focusing of this policy will focus on person-centre, positive behaviour approach, development of transdisciplinary team, communication, and staff development.
Components of values, theory, evidence and process

The authors of Definition and Scope for Positive Behavioural Support (International Journal of Positive Behavioural Support), propose that positive behaviour support is flexible and adaptable and must contain the components of values, theory, evidence and process.

Component 1: Positive behaviour support must be based on these values:
1. Prevention and reduction of challenging behaviour occurs within the context of increased quality of life and social participation
2. Constructional intervention builds stakeholder skills and opportunities and eschews restrictive practices
3. Stakeholder participation informs, implements and validates assessment and intervention practices

Component 2: Positive behaviour support must be theory and evidence base. The basis of understanding is that:
1. Challenging behaviour develops to serve important functions for individuals
2. The primary use of behaviour analysis to assess and support behaviour change is important

Component 3: Positive behaviour support is based on these processes:
1. A data-driven approach to decision-making at every stage
2. Functional assessment to inform function-based intervention
3. Development of interventions to change behaviour (proactively) and to manage behaviour (reactively)
4. Implementation support, monitoring and evaluation of interventions over the long term
Training and supervision

In view of the above components of values, theory and evidence and process, services offering positive behaviour support should meet the specifications including those for a well trained workforce. Specifically;

• each service should emphasizes technical and emotional support. Technical support is largely provided by professional staff and involves supervision and training on technical matters such as care and treatment. Emotional support is due to recognition of the heavy demands of carers working in this field
• all support workers receive training in positive behaviour support practices, which is refreshed at least annually
• all support workers with a leadership role should have completed extensive training in positive behaviour support practices

• all workers with a role in respect of assessing or advising on the use of positive behaviour support practices with individuals should be specifically trained and their training supervised
• all workers involved in the development or implementation of positive behaviour support practices and strategies should receive supervision from an individual with more extensive positive behaviour support training and experience
• workers in consultant roles are supervised by an individual (within or outside the organization) with a relevant postgraduate qualification. In addition, a core competences framework for positive behaviour support should be developed.
Operational values

Management must design support that works. In the literature review the key organizational value that was mentioned was the promotion of service leadership which is fully committed to person-centred practices.

With respect to this, key objectives for effective leadership much be implemented:

Objective 1: Effective planning

Effective leadership:
• sets outcomes and work plans that support person-centred practices which aim to improve quality of life
• ensures appropriate staffing levels required to deliver the service including need for specialist advisors
• establishes the right resources for good workforce development
• realistically costs resources (funding, physical space and time)

Objective 2: Accountability

Effective leadership:
• defines accountability at all levels of service provision
• sets up a code of ethics
• measures and monitors service and worker performance
• addresses poor practice
• ensures whistle blowing policies are in place
• promotes effective sharing of knowledge between services
• celebrates the successes of clients as well as staff

Objective 3: Effective staffing

Effective leadership:
• ensures that workers do not have to work excessively long shifts and have rest periods
• makes responsive rotas based on person-centred plans and or periods of expected high demand (times of the week, seasonal pressures etc)
• ensures workers’ capacity based on person-centred plans and response to fluctuating and/or emergency situations

Objective 4: Effective recruitment

Effective leadership:
• recruits and retains the right workers using competence-based job profiles
• ensures detailed job descriptions and person specifications associated with the job
• ensures that each employee has the necessary skills, qualifications, aptitude and experience
• ensures that new recruits conform to organization values particularly the importance of building a rapport with clients

Objective 5: Supervision

Effective leadership:
• ensures supervision, appraisal and personal development planning
• provides regular, planned supervision as well as ad hoc supervision depending on needs, as they arise
• plans supervision for individuals and groups by someone who has been trained to undertake supervision and who supports the values of the organization
• provides other forms of support namely experts by experience including coaching, shadowing, mentoring or use of “champions” within the service to offer specialized support
• ensures de-briefing which can be a way of offering support and developing learning. It might identify a learning need for an individual worker or team and subsequent amendment to a care plan

**Objective 6: Development of staff skills and knowledge**

Effective leadership:
• identifies the skills and knowledge held within the team
• puts in place learning and development plans to meet any gaps in knowledge and skills to ensure that workers continue to develop
• integrates all training and learning activities about restrictive practices as part of a coherent learning pathway, based on evidence of good practice in that situation, emphasizing positive communication, support for dignified care, and understanding of the functions of behaviour
• offers training on restrictive practices by a trainer who is qualified to deliver and is occupationally and clinically competent
The process of developing a person-centre, positive behaviour approach

Clinically/educationally valid support goes through the following process.

1. Assessment
Assessment for challenging behaviour is the process of collecting and evaluating information about the person, the social, interpersonal and physical environment and the behaviour which is challenging. Assessment should serve to collect enough information to lead to a coherent formulation of support plan which fits the individual and their environment.

*Goodness of fit*
Assessment leading to an intervention plan needs to fit the person and their environment. The concept of ‘goodness of fit’ has been applied recently to interventions for challenging behaviour. Such intervention needs to fit with the values and characteristics of the individual, the people around him/her and their social, cultural or organizational environment.

The design of a programme requires thorough and comprehensive assessment process and analysis of the behaviour itself. It is necessary to know:
- the conditions under which the behaviour occurs
- the operant role it serves the person
- the person’s current relevant behavioural repertoire
- the strengths and weaknesses of the mediating system available to implement treatment

Once this information is gathered, it is summarized in an assessment report following a preset format.

Assessment information should entail the following:

Referral Information
- general particulars
- reasons for referral
- first appearance of behaviour
- course over time
- recent increases and decreases in behaviour
- cycles and other patterns
- account of previous interventions and effectiveness

Client characteristics
- cognitive abilities
- communicative abilities
- motor/perceptual abilities
- self-care skills
- social skills
- community skills
- domestic skills
- leisure/recreation skills
- motivational analysis: likes and dislikes and how they express these
- strengths
- needs

Other information
- family history and background
- living arrangements and placement history
- health and medical status
The environment
- the physical environment - size, comfort, location, safety issues
- the interpersonal setting – relationships and values
- the organizational setting – systems and processes in place to support the person

Analysis of Behaviour
- clear, unambiguous specification and measurement of the target behaviour
- arousal of cycle of behaviour
- course or typical sequence of an episode (including possible precursors/triggers)
- strength, rate, duration, or other measures of intensity
- antecedent analysis:
  - occurrence or absence of
    - settings
    - situations
    - places
    - people
    - time of day, week, month, and year
    - immediate preceding activities, events, and interactions
    - exacerbating events
    - ameliorating events

- consequence analysis:
  - history of management methods
  - current management methods
  - effects of management methods
  - effects of behaviour on others
  - effects on the environment
  - reactions that exacerbate or ameliorate situation

Analysis of meaning:
- hypothesis regarding functions of the behaviour
- hypothesis regarding what events may be suppressing alternative, more acceptable behaviour
- hypothesis regarding stimuli and events discriminative for the behaviour

2. Formulation
Formulation is best regarded as a hypothesis about the nature of challenging behaviour. A formulation should be seen as a working model or map which can be tested through interventions. The formulation should integrate the three basic elements namely the person, the environment and behaviour into a coherent and dynamic whole.

Formulations are often useful within the multi/trans-disciplinary team as a way of helping to co-ordinate and organize thinking and understanding about the individual and their environment.

Formulation provides a guide for clinical/educational action and helps set up criteria for evaluation of intervention. It is essential that a thorough and comprehensive assessment guides the development of a formulation.

3. Intervention
Interventions for challenging behaviour can be divided into reactive and proactive behaviour management strategies.

Clinically/educationally valid support distinguishes between proactive and reactive strategies. Proactive strategies are designed to produce changes over time. Reactive strategies, on the other hand, are those designed to manage the behaviour at the time it occurs.

Reactive strategies
These are interventions which focus on containing behaviour which presents a risk of harm or injury to the person or others, at the time when that behaviour occurs or seems about to occur.
Managing risk
Where aggression or self-injurious behaviour presents a serious risk to the person who is challenging or to others, effective and ethical reactive strategies for managing the behaviour as it happens, or seems about to happen, need to be in place as a matter of urgency.

Duty of care to provide effective interventions
There is an obligation on the person working with behaviour which presents a severe risk to the person, or others, to use his or her skills and knowledge to provide the most effective interventions, available in order to reduce the severity of the challenging behaviour.

Prevention of abuse
No interventions for challenging behaviour should be abusive. A carer must not use interventions which constitute inhuman or degrading treatment. Carers have a duty to report colleagues who are using such interventions, and have a responsibility to prevent such actions.

The intervention should endeavor to protect the person with challenging behaviour by changing the environment or relationship rather than stop the behaviour and thereby silence the person’s protest.

Guidelines on reactive strategies
- The focus of reactive strategies should always be to ensure the safety of the person who is challenging, other clients, staff, family members and any bystanders.
- Reactive strategies are therefore concerned only with managing difficult episodes of behaviour; they are not designed to produce long-term changes in behaviour.
- Reactive strategies should not be used in isolation but must be embedded within a broader programme of intervention designed to produce behavioural change.
- Reactive strategies should follow the principle of least intrusiveness and least restrictiveness. A reactive plan should offer advice on responding to lower levels of challenging behaviour in ways that may help to defuse further behavioural escalation as well as guidance on responding to severe behavioural outbursts.

Non-physical reactive strategies which may be effective include:
- not responding to challenging behaviours at the same time attempting to cue in or reinforce alternative more positive behaviours
- removing demands
- diversion to a reinforcing or compelling event or activity
- strategic capitulation
- low arousal approaches where others stay calm, quiet and non-threatening (e.g. by maintaining appropriate interpersonal space) and try to avoid escalating arousal and the risk of physical violence

- National guidelines have to be developed which provide a clear framework for staff who work in situations in which the implementation of physical interventions may be considered. In such guidelines, procedures for emergency use of restraint, should be very carefully delineated.

Proactive strategies
Included within the category of proactive strategies are ecological changes, positive proactive programming, and focused support. When creating a support plan, all three should be considered.

Ecological Changes
Behaviours occur within a context and often are a function of the person’s physical
and interpersonal environment. Behaviour challenges may reflect a conflict between the person’s needs and environments. As a result, addressing of those conflicts may require a change in environment.

The person’s environment that is the ecological context for behaviour, provide an important aspect of analysis. Challenging behaviour may be impacted by simple ecological changes. Some examples of ecological changes include: changing the person’s setting; changing the number and quality of interactions; changing the instructional methods that are being used; changing instructional goals; and/or removing or controlling environmental pollutants e.g., noise or crowding.

Another necessary ecological change in the interpersonal and programmatic environment is giving the person increased choice and control over their day to day life. Staff needs to acknowledge their responsibility to teach the person how to make increasingly informed choices as the individual may exercise choices primarily to avoid participating in most activities and/or to avoid learning new skills. This may prevent him/her from having the best quality of life.

The model reminds us that ecological strategies hold a position of primacy in our support plans, but that these strategies may need to be balanced by positive proactive programming.

Positive Proactive Programming
Along with ecological change, positive programming has the primary goal of producing durable, generalized outcomes, with good social and clinical/educational validity. In contrast with ecological change, positive programming involves systematic instruction while the former has to do with availability and opportunity.

Positive proactive programming can be described as systematic instruction with an aim to give the individual greater skills to deal better with the environment which will contribute to social integration. It has four main variations which need to be all included in a support plan.

Variations to positive proactive programming
i. The development of general skills across the domestic, vocational, recreational aspects of life.

This centres on creating a new dynamic based on building a repertoire by:
• providing instructional objectives and opportunity to learn and engage in a wide variety of meaningful, appropriate and functional tasks and activities
• provide environments which are not unnatural or contrived to provide opportunities for such tasks

The opportunity to learn and engage in a wide variety of activities thereby provides a fundamental basis for other instructional efforts.

ii. The development of functionally equivalent skills
• this serves a legitimate purpose which aims to increase the functionality of the individual and increase his/her productive and socially acceptable skills and competencies
• must be developed in steps and be developmentally sequenced allowing for adaptation if necessary

Communication
• communication-focused approaches to challenging behaviour should improve the communication skills of both the individual with challenging behaviour and their
communication partners and environments

• with respect to teaching an alternative form of communication, one must take into account the cognitive, sensory, and motor functioning of the person as well as the specific demands made by the different communication systems

• when considering augmentative communication systems, one may choose the options ranging from basic ‘object word card and picture’ systems to sophisticated computerized systems

• instructional communication strategies need to focus on promptness of intervention of the teachable moment that is the opportunity to introduce the new system and prompt its correct use. Each subsequent reinforcement serves to strengthen the new communication response.

The precursor behaviour

• the precursor behaviour itself may represent a more desirable response that could be shaped even further by quickly responding to and reinforcing it before it escalates to the challenging behaviour itself. Focus can be placed on teaching recognition of precursor behaviour and managing it.

Routine response chains

• it is recommended that in routine situations, specifically defined messages that serve a function are taught especially when activities transition to other. These discrete trial prompt-fading procedures help to establish alternative communication response.

iii. The development of functionally related skills

This is instruction and training to teach a specific skill that serves the same function as the challenging behaviour.

• this attempts to identify the communicative function of the challenging behaviour itself and then to replace that behaviour with an equally effective but more socially acceptable one. An example would be teaching an individual to ring a bell rather than throw a tantrum. Both serve to call somebody for help.

• this relies heavily on analysis of the function of behaviour (what is the individual trying to tell me) as well as communication training.

Teaching choice

• positive proactive programming can be directed toward teaching choice-making behaviour and, as this skill is established by giving the person more and more control over his/her day.

• the lack of self-determined options may contribute to challenging behaviour which may be attributed to individuals not having learnt to make choices. This could possibly be due to limited experience that would allow them to make informed choices.

• in cases of profound intellectual disability, this would begin at a very concrete level, using a two-way, forced choice format to select from among a presented pair of items, with one clearly having reinforcement value and the other, neutral value. As a person’s choice making abilities increase, choice making opportunities may be presented at increasingly abstract levels e.g. a person can choose an activity by selecting an object or a picture, she can also participate in scheduling her own day. Organizing a day around a concrete schedule (represented by objects or pictures) is, in its own right, a positive programming strategy to reduce behaviour difficulties.
Schedules
• positive programming can also develop alternative, functionally related although not directly equivalent skills e.g. schedule building, the introduction of contingency specifying stimuli, and establishing stimulus control.
• if choosing an activity provides control, the ability to use a concrete schedule provides predictability. This ensures that the individual is oriented. The person can be oriented to the schedule and shown what activities are planned. He or she might also be reoriented to the schedule at each point of transition, with staff indicating what activity has just been finished, what is about to start, and what will follow.
• in addition to the person being given choices to insert at different points of the sequence, the person may also be taught to follow such a schedule independently, or it can be integrated with teaching choice making.

Contingency planning
• it is important to have a contingency to planned events, just in case the first does not occur e.g. due to bad weather. The individual must have an alternative on the schedule and be instructed accordingly e.g., storm pictures on the picture of beach and subsequently the bus taking them to the venue of the contingency plan.

iv. Coping/tolerance skills

When an individual’s needs cannot be met or s/he cannot cope with and tolerate an environment, the following strategies can be taught to deal with such unavoidable stressors:
• teaching a generalized relaxation response, teaching the individual how to relax when they are feeling stressed or upset.
• another strategy for teaching tolerance is to desensitize a person to those stimuli/conditions that have been associated with the challenging behaviour e.g., desensitizing an individual to a loud noises by cumulatively and progressively introducing noises. This has to be done with extreme caution.

Focused Support
Ecological changes may take time to arrange, and positive proactive programming may require some time before new skills and competencies are mastered. It may therefore be necessary to include focused support strategies for more immediate effects.

The purpose of a focused support strategy is to produce the most rapid, non-aversive effects possible, to reduce the risks associated with the behaviour and to reduce the need for reactive strategies.

Stimulus satiation and antecedent control may, preclude the occurrence of the challenging behaviour altogether. Schedules of reinforcement may further strengthen the ability of a support plan to avoid or minimize the occurrence of challenging behaviour.

4. Evaluation
Evaluation is the measurement of change in order to determine the effectiveness of interventions.

• The evaluation should consider:
  ◦ the severity, frequency and duration of the target challenging behaviour
  ◦ the person’s quality of life and range of activities or opportunities
  ◦ the person’s development of positive skills and abilities
  ◦ the person’s well-being and satisfaction with the intervention
  ◦ the well-being and satisfaction of carers or family members in close contact with the person.
• The evaluation should measure the impact of a specific intervention. For example, interventions that are focused on environmental change should evaluate the success in achieving environmental targets.

• The effectiveness of the intervention should be measured over a period of time. It is recommended that the outcome should be reassessed after one year if an intervention is completed. If the intervention is ongoing, then its impact should be re-assessed regularly, at least on an annual basis and more often if necessary.

• The success and effectiveness of a support plan is not measured by the speed at which behaviour is reduced. Support strategies are evaluated in terms of the durability and generalization of their effects, the side effects they produce, and their social and clinical/educational validity.

• This last outcome requirement is perhaps the most critical as it keeps carers focused on the major point of a support plan that is, not to eliminate the target behaviour per se, but to contribute to the quality of the individual’s life. A support plan has clinical/educational validity if, as a result and through the process of bringing the behaviour itself under control, the person has a better quality of life and s/he has more access, opportunity, choice and mutually gratifying relationships.
Transdisciplinary Team

Provision for challenging behaviour, requires an integrated transdisciplinary approach which would integrate the collaboration of professionals from the fields of social work, psychiatry, psychology, behaviour specialists, speech and language therapy, physiotherapy, nursing and sometimes other relevant disciplines.

There may be dynamics that tend towards a splitting of professional groups and what then appear to be polarized approaches. Yet, in the increasing atmosphere of collaboration between the professions, and the pooling of resources of professional time, support, managerial planning, strategic thinking and research, it is clear that we share more common ground than we have differences and that our greatest effectiveness is when we work in close and coordinated collaboration.

Communication
Communication between professionals, carers and service users, and the timely sharing of information is an essential component of care. Timely communication and content of reports, need to be adhered to as an essential element of good practice. A system of care coordination is an essential mechanism.

Feedback
This includes verbal and informal communication between professionals, carers and service users. Feedback should be provided at several stages, as follows
• at the end of the assessment period and at formulation of plan
• following intervention to determine whether or not intervention was successful
• when there is a substantial need for revision to the formulation or the proposed intervention plan
• on completion of work with the individual or care team

Professionals, carers and service users involved in the assessment or intervention should receive regular and routine feedback, ideally by the appointed key worker. This, of course, is dependent upon appropriate consideration of issues of confidentiality.

Furthermore, feedback should also be given to the individual with challenging behaviour in an understandable and respectful form.

Set backs
The scarcity of some categories of staff (e.g. speech and language therapists, behavioural therapists) presents an obstacle to the development of a transdisciplinary model, particularly given the specialized nature of the expertise required as well as the shortage of staff in this field.

However, good team working, supervision and debriefing are important. Effective behaviour support is dependent on achieving genuinely multi-disciplinary working.
Communication

The five good communication standards mentioned in the literature review are further discussed below and set as guidelines:

Standard 1: There is a detailed description of how best to communicate with individuals.

One should have a clear description of an individual’s communication and this description should include information on the extent of the individual’s:

- hearing, concentration, memory, comprehension of words and sentence, understanding of contexts, non-verbal language
- expression of words and sentences, clarity of speech, reference to signs, symbols, facial expression and body language
- intent to communicate
- understanding other’s intent to communicate
- understanding what makes a good communication environment e.g. noise, space, sensory information

Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

- inclusive communication is an approach that seeks to create an effective communication environment using every available means of communication
- for services to demonstrate involvement, innovative and creative solutions to understanding the views of individuals are often due to the nature of communication needs

Standard 3: Staff value and use the best approaches to communication competently with each individual they support.

- staff must recognize communication difficulties and might often need a change in their communications style to support the service user. Staff must have the knowledge and skill to adapt their communication levels, styles and methods
- staff should be aware of factors that impact on communication especially hearing and sight and sensory regulation
- staff should also understand how good communication underpins informed consent

Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate by:

- providing a welcoming, socially rich environment which is central to the wellbeing of individuals. It gives individuals the opportunity to communicate about anything
- good communication needs to be considered broadly and in terms of all social interactions such as greetings and sharing stories. It is the quality of interaction that contributes to the overall emotional and mental wellbeing and provides a sense of belonging and involvement

Standard 5: Individuals are supported to understand and express their needs in relation to their health and wellbeing.

- the individual with challenging behaviour may have limited communication capacity
and may encounter difficulty to effectively convey health needs to others

- arriving at a diagnosis can prove difficult if a person cannot describe symptoms easily or their behaviour is misunderstood or misconstrued. Staff needs to be aware of how individuals communicate about their health and how they show that they are in pain. This includes considering pain or illness as cause for changes in behaviour

- it is essential to consider the individual’s communication capacity and communication needs in order to support him/her with their health
Conclusion

This policy has sought to present an understanding of disabled persons who have challenging behaviour, and through such an understanding provide information that will allow for appropriate positive behaviour programming. The aim of these guidelines set out in this policy is thus to act as a stimulus to improve practice as well as provide common practices.

The authors of this policy feel that there are critical matters that should be addressed further. These are the creation of legislative instruments relating to reactive measures, the setting up of a code of ethics for workers and service providers, commissioning a national audit of resources as well as the setting up of an independent regulatory body to oversee and ensure effective practice. Furthermore, the participants in the consultation process emphasized the need for a wide-ranging, public awareness campaign which would also target specific target groups, such as teachers, LSAs and parents. The main concern was to sensitize these groups about challenging behaviour and the reason why it happens, all this in a bid to remove stigma and segregation and to improve the quality of life of individuals with disability whose behaviour represent a challenge to themselves and to others.
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Policy and guidelines on working with disabled persons with challenging behaviour

Part of ESF3.105 ‘Promoting the social inclusion of disabled persons with challenging behaviour’

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