National Disability Services Quality Improvement Office
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A Rights Based Approach to Behavioural Support

Guiding Principles

Preamble: There is an acknowledged connection between human rights and well-being: the more rights you hold and can express the better your well-being. There is a history of human rights concerns in the supports a person with intellectual disability receives. These concerns increase when a person is given a label of 'challenging behaviour', 'behaviours that challenge', 'behaviour of concern', etc. These labels were created to put the focus on supports and services so that they become capable and responsive to each person's needs. Unfortunately, these labels have become associated with the person only and have not been seen as the responsibility of the service and supports, as in the duty bearer is now correctly placed and aligned with their responsibilities to the rights holder. Behavioural support addresses wants, needs and rights of the person. These guidelines advocate that going forward each person with behavioural support needs has access to a Human Rights informed, evidenced based behavioural support model in a compassionate, empathic and collaborative way so that there is an understanding of the person's needs so that supports are provided that are liked and agreed to by the person in order to achieve valued outcomes for everyone involved. We all behave and at times, we can all behave in unsafe ways. Behaviour is part of our common humanity, it is how we communicate and express ourselves.

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Introduction:

These Guiding Principles are intended to support services when revising their local policies and procedures developed to meet the Schedule V requirements of the Health Act 2007 (Care and Support of Residents in Designated Centres for persons with disabilities) Regulations 2013.

The Guiding Principles: (page 3)

The set of Guiding Principles has been developed following an international literature review which was validated using the AGREE tool (Appendix III) along with the preferences and views elicited from service users. These Guiding Principles reflect the key elements that should be incorporated in your local policy and procedure. The references which were used to identify these principles are attached to the end of the Guiding Principles document.

Definition:

For the purpose of this document behavioural support is defined as using a 'Human Rights informed, evidenced based behavioural support model in a compassionate, empathic and collaborative way to understand the needs and concerns of the person and provide supports that are liked and agreed to by the person in order to achieve valued outcomes for everyone involved.'

Behavioural support may be required if a person's behaviour is interfering with their ability to maintain their relationships, engage in a meaningful life and express themselves in ways that do not cause themselves or others harm.

It is recognised that there are a number of behavioural support models. This guideline does not recommend any specific model instead it outlines what a behavioural support policy should include for a person requiring behavioural support.

Person: In this document a person is used when referring to a child and/or an adult.

Harm: In this document harm is understood as

> 'The impact of abuse, exploitation or neglect on the person. Harm arises from any action, whether by a deliberate act or an omission, that may cause impairment of physical, intellectual, emotional , or mental health and well-being.' HSE National Safeguarding Office, *Final Draft HSE Adult Safeguarding Policy (2019)* (HSE June 2019).

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Impact Assessment (Appendix I) – (page 13)

This Impact Assessment has been developed to assist services during the implementation of and revision of local policy and procedure and is intended as a guide to provide a structure for measuring the impact of the revised policy in four key areas:

1. Stakeholder Perspective
2. Internal Business Processes Perspective
3. Learning and Growth Perspective
4. Financial Perspective

This tool should be used by the local policy and procedure development or steering group when the policy revision is close to completion. There is an action plan to record what needs to happen under each of the four headings to support the implementation of the policy.

Audit Tool (Appendix II) – (page 19)

This document is intended to act as an audit tool when a service is revising their local policy and procedure. The purpose is to ensure that each of the questions in the audit tool is addressed in the local policy and procedure. This includes a question at the end of the audit tool to ensure that experts by experience or people who use the service have been involved in developing or reviewing the behavioural support policy in a meaningful way.

Verification of Literature using AGREE Tool (Appendix III) – (page 20)

This document is included in the packet to assure services that the Guiding Principles were developed in a robust manner and that the literature was validated against this accredited tool (AGREE) as well as giving a synopsis of the engagement with service users. It is for information purposes.

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Rights Based Behavioural Supports Guiding Principles:

The National Guiding Principles Group, under the auspices of the National Quality Improvement Office, HSE Disability Operations, has identified eight (8) guiding principles to assist organisations in developing and revising local policies and procedures for the provision of behavioural supports.

The following 8 guiding principles are evidenced in the services local policy and procedure that guides their provision of behavioural supports:

1. Use a Human Rights Model (HRM): Supporting persons to live lives of their choosing informed by human rights.

1.1 Human Rights Model underpins all supports (to include behavioural supports) to a person. A HRM is delivered through a Human Rights Based Approach which has five core principles (PANEL) (HIQA uses FREDA, which can also be applied).

a. **Participation**-everyone is entitled to active participation in decision-making processes which shape their lives and affect the enjoyment of their rights. They must know what their rights are, be supported to understand them if necessary and have the opportunity to influence decisions affecting them.

b. **Accountability** – Those responsible (duty bearers) for respecting, protecting and fulfilling human rights must be accountable for their actions or their failures to act. There should be effective strategies in place to identify rights infringements and remedies in place when human rights breaches occur. This includes advocating with the person.

c. **Non-discrimination and equality** – all individuals are entitled to their rights without discrimination of any kind. A HRBA requires that laws and practices guarantee full and equal enjoyment of human rights to vulnerable groups on the same basis as anyone else. In order to achieve this, these groups may require a special focus. All types of discrimination should be prohibited, prevented and eliminated.

d. **Empowerment** – everyone is entitled to claim and exercise their rights. People must be educated about their rights, equipped with the necessary skills to claim them and participate in the development of policies which affect their lives. This represents a shift from models which see people as being in need or as passive recipients of charity, but instead views them as people empowered to claim their rights.

e. **Legality** – Human rights must be at the heart of policymaking and service delivery. Approaches should be in line with the legal rights set out in Irish and international laws. This includes identifying and naming the rights that the person may not be supported to exercise or that may be restricted.

1.2 The rights and voice of each person are recognised: A complete, dynamic profile of the person's communication strengths and needs should be gathered and communication

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supports based on this assessment, for example a Communication Passport, be put in place in line with the organisation's communication policy. All staff should be trained and/or advised on the person's communication needs. The voice of the person must be central to the co-development of their behavioural supports. This includes access to an advocate if required.

1.3 A person centred approach is evidenced for each adult; and a child centred, family centred approach is evidenced for children in the resultant policy. Persons who access and use services (together with their families as appropriate) are equal partners in planning, developing and monitoring their care and support to make sure it meets their needs. The strengths, capabilities, and unique circumstances and needs of each person and/or their families (as appropriate) are recognised and included in person centred, child and family centred, care and support plans.

1.4 Effective and ethical behavioural support, acknowledges the importance of a capable and responsive environment (for example-where the person lives, who they live with, relationships they have, what activities they engage in and the skills of the people who provide their support, etc.) on a person's well-being and stress. If an environment is unable or incapable of meeting a person's needs, this is identified together with the person and advocacy is accessed, as required. A plan (business plan, for example DSMAT), to build a better service or refer to an alternative service where the person's needs and concerns can be met, may be required. If there is a risk to the person or other people the Safeguarding Policy and the complaints policy is referenced and adhered to.

1.5 Quality of Life Outcomes define effective behavioural supports: behavioural support includes supports to enable each person to improve their quality of life, for example by supporting the person to have:

- Meaningful and enduring relationships (which includes intimate relationships);
- A place to call home, (living with people who love and care about them and who they love and care about.);
- Meaningful and socially valued roles; for example, employment; skills for independence etc.;
- Fun, joy, pleasure and love;
- Effective ways to communicate, to exercise choice, power and control;
- On-going education, support and advocacy opportunities (for self, citizen advocacy, disability activist organisation participation for example);
- Skills and supports to be safe and healthy, to maximise feelings of well-being, value and worth;
- Opportunities for personal development and reflection; for example, coping skills for resilience, problem solving, communication skills (expressive and receptive), self-awareness, psychological therapy, etc.

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2 Compliance with current legislation, national policy, research and human rights framework, and any relevant future amendments to support persons to live according to their will and preference.

Each services' policy will reference relevant legislation, national policy and research:
For example:

- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- European Commission for Human Rights (ECHR).
- Assisted Decision Making Act (ADM)
- Health Act 2007
- HSE relevant policies, for example, Safeguarding Policy, Open Disclosure, National Consent Policy etc.
- Time to Move on from Congregated Settings: A Strategy for Community Inclusion
- New Directions Personal Support Services for Adults with Disabilities

3 Understanding needs and concerns as expressed/communicated through behaviours (bio-psycho-social-environment model)

3.1 A commitment to using an assessment process to seek/listen to and learn/respond to the unmet need expressed through behaviour is outlined in the policy. All behaviour communicates a message. A complete, dynamic profile of the person's communication strengths and needs should be gathered, adopting a total communication approach and valuing all modes of communication utilised by the individual, both receptively and expressively. Each assessment(s) must try to uncover the meaning of the behaviour. The subsequent plan of supports must be based on the meaning of the behaviour.

3.2 A person's needs' can be complex and indeed the assessment may need to explore many factors to understand the needs of the person. Assessment for behavioural supports may need to take into account many factors; for example; physical health, mental health, biological factors, communication style and preference; memory needs, sensory processing needs, neurological factors; skill(s)strengths and deficits; life story; history of behavioural support needs, valued roles; motor challenges, preferences and fun; adverse life events which may include trauma; anxiety; stressors; learning style; functional assessment; autonomy and choices; worries and emotional distress; psychological factors; environmental factors; use of technology; attachment and relationship needs; executive function skills (ability to regulate frustration/tolerance; flexibility; affect regulation) etc. Effective assessment results in a shared understanding of the person's experiences and needs by integrating biological, psychological, environmental and social factors.

3.3 Collaborative behavioural support is in place which evidence that the person, their friends/family and others (as appropriate) have engaged in problem-solving together, leading to co-development of solutions for the support needs of the person and those around them.

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3.4 Supports and Interventions are research informed and evidenced based and are in line with a Human Rights Model. Supports and interventions are written down in person first language and contained in the person centred plan. Supports and interventions are predominantly designed to be proactive and preventative. The behavioural support being provided should be acceptable to, and agreed with, the person and others supporting the person (if appropriate).

3.5 Valued Outcomes guide and define effective behavioural support: The person (and their circle of support as appropriate) identifies a range of valued outcomes they wish to achieve as a result of behavioural support. For example:

- The Quality of Life Outcomes described under 1.5
- Financial Independence etc.

These are documented and reviewed.

3.6 Interdisciplinary working can be critical in understanding behavioural support needs and it should be tailored to the person's needs and concerns. Any clinician in any discipline may have an important role in understanding and helping a person who has behavioural support needs. These clinicians may include, for example the following: Behaviour Support Practitioner, Occupational Therapy, Speech and Language Therapist, Social Work, Physiotherapy, Nursing, Social care, GP, Psychology, psychological therapist, Creative Arts Therapies, Psychiatrist, Advocate, Specialist Consultant etc.

4. Sufficient oversight

4.1 Effective supports are reviewed and evaluated against a person's desired outcomes, lifestyle choices and indicators of well-being. The HSE nine outcomes and/or the UNCRPD can also be used to measure outcomes achieved. For children, the *Outcomes for Children and their Families Framework (OCFF 2013),* which identifies six desired outcomes for children and five desired outcomes for families, can be used to measure the extent to which the supports offered provide desired outcomes. Collaborative review occurs using a range of information, for example conversation with the person, spending time with the person, checking in with their circle of support, their family, if appropriate and other documentation and measures that may be appropriate.

5 Ongoing practice, education, and support

5.1 Supports for team building, collaborative problem solving, mentoring, training and education, supervision, de-briefing and coaching for key stakeholders (for example staff, family members, teachers, pre-school staff, respite staff, family support workers, care staff, special needs assistants) are considered and facilitated as required. This enables a team based, supported, shared understanding and approach to the provision of behavioural supports.

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5.2 There are appropriately qualified practitioner(s) providing behavioural supports in the service who are registered with an appropriate professional body and have access to professional supervision. Such practitioners should be working within, or with access to, an interdisciplinary /multi-disciplinary team which may include primary care, mental health and intellectual disability teams.

5.3 Reflective practice, supervision and leadership is essential for safe practice.

6. Decision making and problem solving when balancing safety, risk of harm, and freedom of choice.

6.1 Informed decision making in line with the Assisted Decision Making (Capacity) Act and a Human Rights Model is evidenced.

6.2 Positive risk taking is encouraged and supported.

6.3 Each person is safe and free from abuse and harm. (Safeguarding policy is adhered to.)

6.4 Towards the prevention, reduction and safe use of Restrictive Practices, HSE Guideline document is referenced and evidenced.

7. Responding in the moment to the person's need:

7.1 This must involve responding to and supporting the person's need to be met, the need being communicated through the behaviour. This may involve facilitating the person to release emotion or excess energy, to leave an environment that is too noisy, to have something to eat, etc. If the message/need being communicated is not clear or cannot, in the moment, be responded to, strategies such as active listening, facilitated relaxation, etc. might be appropriate. The person, when calm, or at another time, may be supported to problem solve on how best to respond if they need support to regain composure in the future.

7.2 Understanding and supporting the person's needs when the person does not have the communication or other skills to express or meet their needs requires those supporting the person to be fully mentally aware and present, physically relaxed and genuinely accepting of the person's needs.

7.3 The support and response provided at this time is always evidencing a commitment to the non-use of any restrictive, aversive or punitive means.

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8. Language and terminology

8.1 Behavioural Supports policy /guidelines are accessible, jargon free, and written in Plain English.

8.2 Materials and technology are used and adapted to best meet the person's needs and abilities to understand behavioural support information.

8.3 Each person has the support required to understand information and express themselves in a manner that is accessible to them.

8.4 Communication partners are suitably trained qualified professionals who value and adapt to a person's communication style and are competent to use a variety of communication approaches, as appropriate to the person.

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APPENDIX I – Impact Assessment

Impact Assessment:

The purpose of an impact assessment is to 'assist leaders to fully understand the extent and complicity of the change' and will ensure that an integrated approach to managing the change is adopted (McAuliffe *et al.*, 2006). The Balanced Score Card provides a structure for measuring Impact (Kaplan & Norton, 1993). It has 4 key areas and as the name suggests we need to keep a balanced approach to all four. We also need to pay attention to how these interact with each other- for example training and education for staff may be a requirement to introduce something new- how does that impact on finances?

- **Stakeholder Perspective:** This perspective is about how the Policy will impact on stakeholders.

- **Internal Business Processes Perspective:** This perspective ensures the stability and sound operation of your business. What systems/ structures/ referrals/ recording do you need to change or introduce to fully implement this policy?

- **Learning and Growth Perspective:** This perspective consists of training and improvements required for the workforce to implement the policy. It ensures that your employees have the skills to implement the policy. This area also considers the need for data relating to the implementation of a policy- do you need records of how the policy is implemented, eg- the number of referrals to a department, the number of staff who have been trained? Do you need an audit tool?

- **Financial Perspective:** This perspective indicates whether your Policy impacts on the bottom line. Not for profit companies consider the financial perspective last. This however is often a challenging area in public service and requires attention before a policy is 'launched' into a system that is not financially able to support its implementation/ sustainment.

There are a series of questions for each of the four areas of the Balanced Score Card that should be considered by a Policy Steering Group/ Policy Development Group when the policy is close to completion. There is an action plan to record what needs to happen under each of the four headings to support the implementation of the policy.

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1: Stakeholders; who does the policy impact on? What level of impact is there? How do we engage with the stakeholders to maximise the positive impact of the policy and minimise the perceived negative impact of the Policy?

Name of Stakeholder	**How much are they affected? (High/Med/Low)**	**How much influence do they have on the implementation of the policy? (High/Med/Low)**	**Do we have a plan to engage with/ inform this stakeholder about the policy?**
Service Users			
Families			
Clinical staff			
Frontline staff			
Local Managers/ PIC's			
Senior Managers/ Regional Managers			
CHO Disability Managers			
National Disability Team			
HIQA			
Voluntary Agencies			
Other agencies / service providers			

Actions required relating to stakeholders:

1.

2.

3.

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2: Internal Processes: How will this Policy impact on internal processes?

Operations Management: delivering services to service users:

Is there a current practice/ procedure that needs to change?

Do we have a governance structure to support the implementation of the policy?

Do we need to develop/ update assessment process associated with this policy?

Is there a new/ updated referral pathway required?

Do all staff know how to access information/ training/ support to implement the policy?

Do we have a review process in place for the policy?

Do we need resources (eg- new equipment/ access to computers, access to documents/ etc)

Regulatory Requirements – Does this Policy support compliance with a set of regulations?

What will the impact be on the compliance levels?

Does it have an impact on GDPR compliance?

Does it have an impact on Assisted Decision Making (Capacity Act)

Does it support compliance with the Health Act?

Does it support the introduction of New Directions for Day Services?

Are there other regulatory implications? (eg- Health and Safety Legislation, Safeguarding Policy requirements,

Are there regulatory risks associated with implementing the policy?

Actions required relating to internal processes:

1.

2.

3.

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3: Learning and Growth: How will this Policy impact on learning and growth needs in the organisation?

Data:

- Is there accurate, timely and complete information available to make management decisions?
- What data is available and what data is required?
- Can we leverage the data we have to support the implementation of this policy?
- What data will help us to report on the implementation of this policy?

Training:

- Are education and training interventions required?
- Do we have a training provider who will provide training?
- Have we considered how many staff will need training and education?
- Can we record staff training and include it in HR records?
- Are there 'backfill' costs for staff to attend the training?
- Is it going to be 'mandatory' training?
- Can we do some online elements?
- Is the training based on the Policy?

HR/IR:

- Are there IR/ HR issues to be dealt with?
- Are there role specific HR implications?
- Do job descriptions need to be updated?
- Do we need to engage with representative bodies/unions/professional bodies?
- Are the management team clear about the processes for implementing this policy and their role in it?
- Do we have a HR process to manage people who do not implement the policy?
- Do we need new posts to support this policy? Do we have agreement that these posts can be filled?

Actions required relating to Learning and Growth:

1.

2.

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3.

3: Finances: How will the implementation of this Policy impact on Finances?

- Have we considered the financial implications associated with the policy?
- Consider: staffing, new equipment, training, new data collection systems, computers/ hardware/software/
- Where will the costs be located: Locally? Regionally? Organisationally? Nationally?
- Is there an agreement in place to fund the implementation of the policy?
- If funding is not available are we going to do it anyway? – is this sustainable?
- Do we need to pilot it and examine the cost of implementation before a wider role out?
- Are there risks associated with finances?

Actions required relating to Finances:

1.

2.

3.

References:

Kaplan, R. and Norton, D. (1993). Putting the Balanced Scorecard to Work. [online] Harvard Business Review. Available at: https://scanmail.trustwave.com/?c=6600&d=mtOP3Hd_PgUW7QSSAIx5Gk_RqyLJQxm3v95eDITWTQ&s=343&u=https%3a%2f%2fhbr%2eorg%2f1993%2f09%2fputting-the-balanced-scorecard-to-work [Accessed 8 Jan. 2018].

McAuliffe, E. *et al.* (2006) *Guiding change in the Irish health system*. Report. Health Service Executive (HSE). Available at: http://www.lenus.ie/hse/handle/10147/78553 (Accessed: 8 February 2018).

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APPENDIX II – Audit Tool

Organisations/ Local Communication Policy Audit Tool: Provisions for Behavioural Support

Guiding Principles to be included in Provisions for Behavioural Support policy	Yes/ No	Action Required
Does the policy define what behavioural supports are?		
Does the policy set out how the person will be supported to make choices in how they are supported?		
Does the policy set out how the person will be supported to live lives of their choosing informed by a Human Rights Model and a Human Rights Based Approach?		
Does the policy provide guidance on how to ensure a person's voice is heard?		
Does the policy include guidance on responding in the moment to a person's need?		
Does the policy include guidance on the complexity of "behaviours"?		
Does the policy comply with the most current legislation, national policy and research and human rights framework?		
Does the policy recognise the importance of a Person Centred Approach in supporting the person's unique goals and to improve Quality of Living?		
Does the policy provide clear guidance on governance and oversight measures?		
Does the policy support ongoing practice, education and support for staff?		
Does the policy support the positive risk taking?		
Does the policy highlight the need to work towards prevention, reduction and safe use of Restrictive Practices?		
Does the policy use accessible language and terminology, free from jargon?		
Does the policy give guidance on suitable communication supports depending on the person's needs?		
Have experts by experience or people who use the service been involved in developing or reviewing the policy in a meaningful way?		

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Appendix III – AGREE Tool

Preparation for validation of research - adapted from Agree Checklist[1] To be used by working groups to document and present research undertaken in developing a policy for review by the Expert Group within the Guiding Principles Group

Title of SET OF GUIDING PRINCIPLES: Provision of Behavioural Support

DOMAIN 1: Scope and Purpose

1.1. The purpose of this set of Guiding Principles is:

a. To define best practice in relation to the provision of behavioural support with adults and children with a disability
b. To provide a support to services when developing or revising their local policies for the Provision of Behavioural Support (Schedule V no. 5, Health Care Act 2007, Regulations 2013) to ensure they are in line with best practice.

The scope of this set of Guiding Principles is:

1.1.1. Describe the population (staff, people who use services etc.) to whom the set of Guiding Principles *will apply*

This policy applies to all:

- Staff
- Volunteers
- Students on placement

involved in supporting adults and children with a disability in HSE provided and HSE funded day and residential services. This also includes adults with a dual diagnosis of intellectual disability and another diagnosis (e.g. physical disability / sensory disability, autism spectrum disorder, mental health diagnosis etc.).

1.1.2. Outside the scope of the set of Guiding Principles (CAMHS and AMHS?)

1.2. OBJECTIVES

Report the overall objective(s) of the set of Guiding Principles *:*

- To provide a set of Guiding Principles that can be used to support the development of Provision of Behavioural Support local policies where they do not exist.
- To provide a benchmarking tool for services where Provision of Behavioural Support policies do exist to allow the existing policy to be reviewed to bring them in line with best practice.

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1.3. OUTCOMES:

The Outcomes of the Implementation of the Provision of Behavioural Support Guiding Principles are:

- Improved Behavioural supports for adults and children with a disability.
- Increased use of effective Behavioural supports by staff, which are respectful of the individual and based on the individual's needs and preferences.
- Improved staff knowledge and skills to deliver high quality Behavioural supports.
- Improved staff understanding about the importance of implementing rights based Behavioural supports.

1.4. QUESTIONS

Report the policy questions – SPIDER questions (Sample, Phenomenon of interest, Design, Evaluation, Research Type) covered by the set of Guiding Principles, particularly for the key recommendations:

The **Provision of Behavioural Support** Guiding Principles are based on five Clinical Questions and a research strategy for each was developed:

1. What are effective supports for adults or children who have challenging behaviour?

S: individuals with challenging behaviour
Pi: interventions, supports
D: N/A
E: experiences
R: qualitative/ quantitative

2. What factors contribute to challenging behaviours?

S: individuals with Pi: causal factors (e.g. bio-psycho-social- environmental) understanding for example, physical /medical needs, stress, attachment, trauma, executive function, mood, anxiety, noise)
D: N/A
E: N/A
R: qualitative/quantitative

3. How does rights based approach support the provision of effective Behavioural supports?

S: individuals with challenging behaviour
Pi: rights based approach
D: N/A
E: experiences
R: qualitative/quantitative

4. What is the role of frontline staff and multidisciplinary team in providing Behavioural supports?

S: individuals, staff, MDT.
Pi: role of staff and MDT
D: N/A
E: experiences
R: qualitative

5. What behavioural supports are person-centred or family centred?

S: individuals with
Pi: person-centred or family-centred supports
D: N/A
E: experiences
R: qualitative/quantitative

DOMAIN 2: STAKEHOLDER INVOLVEMENT

2.1 GROUP MEMBERSHIP

Report all individuals who were involved in the development process. This may include members of the steering group, the research team involved in selecting and reviewing/rating the evidence and individuals involved in formulating the final recommendations.

The working group is comprised of:

1. Marie Kehoe-O'Sullivan, National Quality Improvement Office, HSE Disabilities (Chair)
2. Nicole Lam, Research Officer, National QI Office, HSE Disabilities
3. Ruth Connolly, Psychologist, Muiriosa Foundation
4. Geraldyn Jackman, Quality Partner, Cheshire Ireland
5. Adrienne Smith, Service Manager, Camphill
6. Keith Lyons, Psychologist, StewartsCare
7. Fiona Shanahan, CNM3, Cheeverstown
8. Kirsi Salo, Assistant Director, Inspire Wellbeing
9. Angela Colgan, Clinical Nurse Specialist, Stewart's Care
10. Brian McClean, Psychologist, ABI
11. Edel Carey, ANP, HSE
12. Elizabeth McGrattan, Practice Development Coordinator, Peamount
13. Marian Murphy, Training and Development Manager, Western Care
14. Toby Sachsenmaier, Psychologist, Clare Children's Service
15. Mary O'Connor, NMPDU
16. Maria Walls, PhD Candidate, NUI Galway
17. Stephanie Kilrane, Director of Quality, Risk and Safety, Daughters of Charity
18. Therese Crosbie, Occupational Therapist, Talbot group
19. Mary Hurley, Occupational Therapist, Daughters of Charity
20. Caroline Dench, Coordinator, Callan Institute, Saint. John of God Community Services clg.
21. Karen Henderson, Speech and Language Therapist, Cheeverstown
22. Gary Brennan, Development Officer, Prader-Willi Syndrome Association Ireland
23. Padraig Manning, HSE librarian
24. Catherine Jackman, Psychologist, Cheeverstown services

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2.2 TARGET POPULATION PREFERENCES AND VIEWS

Report how the views and preferences of the target population were sought /considered and what the resulting outcomes were.

Two service user consultations took place in two different services. Both sessions were facilitated by staff that knew the service users well. Service users were asked questions that were developed by the working group. Below is a summary of the questions and answers found in both services.

1. What is your idea of a good life?
    - Chatting to and seeing friends
    - Independence and getting around, want to be on their own
    - Being educated and gaining more knowledge
    - Social and sport events BUT unable to do a lot of things due to lack of drivers. Would like to see their friends more often.
    - Go on the bus and go shopping in town
    - Living with family
    - Independence, having a job to earn money and go on holidays

2. What happens if you can't have a good life?
    - Ask staff and family, talk to friends
    - Stand up and speak out
    - Go mad if they (staff or other people) don't listen to them
    - Service users were very aware of the chain of command, named their key worker, the manager and then the CEO as staff to approach if they wanted to escalate a concern
    - Feel stuck in the house
    - Ask friends for advice
    - 5 out of 7 have made a formal complaint before

3. How do people react if they are upset?
    - Cry, scream, shout
    - Throwing things
    - Temper tantrums
    - Banging things
    - "get angry"

How can others help?

- They ask each other what's wrong?
- Friends help one another
- Talk and calm them down
- They want staff to be calm as well, tell them they are their friend.
- Regular staff know their unique and individual needs
- A few indicated preference for regular staff as opposed to agency/new staff who "talk to the manager, not you", they don't listen as much. Some were ambivalent and trusted any staff member.

4. Do you know what rights are?
    - Friends/social life
    - Privacy – no one in their room
    - Voting, passport, travelling – citizenship
    - Education
    - Accessibility: wheelchairs, ramps sign language.
    - One individual highlighted that their home is not accessible to their friend, whose wheelchair cannot fit through the front door.
    - Safety and feeling safe in own home
    - Ramp outside one individual's home is uneven and their chair gets stuck.

5. Is it ok for a staff to take away a right to keep others and the individual safe?
    - No one's rights should be taken away
    - But staff need to be there sometimes to support individuals, e.g to use the toilet
    - If someone is upset on the bus they should still be allowed out in town instead of returning home and stopping the trip. They should try and calm them down, relax, and find out alternative ways to support them.
    - Bringing someone out of the room is ok if they hurt someone else and others are frightened. If others rights are infringed upon, it is ok to take it away.
    - Conflicting opinions on seclusion, only okay if someone else is hurt
    - What is more important: safety or rights? 4 said safety was more important than rights, 3 said rights were more important.

DOMAIN 3: RIGOUR OF DEVELOPMENT

3.1 SEARCH METHODS

Report details of the strategy used to search for evidence:

A review of Gray Literature was conducted, including provision of behavior support policies in existence in Disability Services in Ireland, as well as international literature search.

A primary literature search was conducted using PICO and key words that were suggested by the working group members, yielding 43 articles. However, the group felt a more qualitative perspective, especially from a Human rights based approach was needed and a secondary search was conducted using the SPIDER questions. A total of 26 articles were found. Seven articles were repeated from the first search. A snowball search was conducted by a group member to extrapolate a better understanding of what behaviours mean. The two literature reviews were conducted by the HSE librarian including a full search of CINAHL, MEDLINE, SOCINDEX and EBSCO DISCOVERY

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3.2 EVIDENCE SELECTION CRITERIA

Report the criteria used to select (i.e., include and exclude) the evidence. Provide rationale, where appropriate:

The primary literature review excluded articles that were too clinical or not relevant to the topics.

3.3 STRENGTHS & LIMITATIONS OF THE EVIDENCE

Describe the strengths and limitations of the evidence. Consider from the perspective of the individual studies and the body of evidence aggregated across all the studies.

Key questions to answer:

3.3.1 Are the results valid?

The literature review **did** identify systematic reviews and meta-analysis in relation to the provision of Behavioural supports for adults with a disability.

Positive behaviour supports or PBS is frequently cited as the most effective approach in behaviour supports. Proponents of PBS highlight the multi-dimensional approach it takes as a framework for behaviour supports. According to McClean and Grey (2012), PBS emphasises four areas of interventions: 1. proactively changing the environment specific to the individual before the problem behaviour occurs; 2. teaching individual skills such as self-management and communicational training; 3. reinforce appropriate behaviours; 4. Direct interventions which may include responding safely in order to reduce the episodic severity of the behaviour and mitigate for the use of punitive, aversive and/or restrictive interventions. (Grey, et al., 2018, LaVigna et al 2002). PBS uses an inter-i-disciplinary approach which draws from the evidence base in social, behavioural, educational, and biomedical science and applies this evidence base with practical strategies (Perez, et al., 2012). It is most frequently used as it is considered the most comprehensive approach and it is person-centred and focuses on the individual's quality of life (Hieneman, 2015).

Not all articles agreed that PBS was the ideal approach for behaviour supports. Feeley and Jones (2006) and Woolls (2011) outline the origins of PBS and how it derived from Applied Behaviour Analysis or ABA intervention. Both outline the negative connotations associated with the old ABA approach which considered certain behaviours to be "undesirable" or individuals to be "deficit". The effectiveness of ABA is largely criticised for framing behaviours and thus the individuals as a risk or dangerous and leading to restrictive practices, inappropriate medical use, restraint, and punishment (Baker and Allen, 2012). This led to the emergence of PBS which integrated the evidence based approach of ABA within a more comprehensive and integrated scientific understanding and application of biological, psychological, social and environmental theories relevant for the application of behavioural support. However, some argue that it is an imperfect approach that is still vulnerable to corruption and that it is still paternalistic, just like the ABA it was meant to replace. Others argue the efficacy of PBS and suggest that it is only useful for people with less severe intellectual disabilities or challenging behaviours. Studies that examine the effectiveness of PBS have shown mixed results depending on many factors including the population and the actual interventions used, although the outcomes are largely positive. The Multi-Element Behaviour Support Model, which is a comprehensive framework for the application of PBS principles has evidenced that PBS is an effective science when applied by

trained practitioners in the context of the evidence based research. See references)
(Callan Institute, Saint John of God Community Services has been successfully using this behavioural support model in Ireland for the last 28 years.)

A human rights based approach (HRBA) recognises individuals supported as rights holders. individual's quality of life, environmental changes and opportunities for personal development and an individualised understanding of behaviours are all considered important contributors to successfully support the individual. Instead of focusing on reduction of behaviours as the primary focus in a support plan, addressing rights and improving quality of life can shift the focus and responsibility away from the individual (Dunlap et al., 2008; Keen and Knox, 2004) and onto the duty bearer which aligns this with a Human Rights Model In order for this to be achieved, supports should include strategies focused on personal development, for example, opportunities for learning, reflections, therapy, increasing emotional resiliency for the individual (Grey, Lydon and Healy, 2016) alongside suitable environmental supports or changes (Matson et al., 2010). Supports should be aware of mismatches between the individual and the environment (Tolisano, Sondik and Dike, 2017; Walsh et al., 2018). Studies on the efficacy on mindfulness for staff and individuals report a reduction of aggressive incidents/behavioural dysregulation among individuals who were taught mindfulness techniques (Thomas, 2013; Wupperman et al., 2015). It enables individuals to experience the moment of negative emotions without engaging in behaviours that are undesirable, and allows them to express it mindfully.

Changes in the service are necessary to support staff to more effectively support individuals, especially in areas of continuous training and improving workplace culture (Doody, 2009; MacDonald, McGill and Murphy, 2018). Training should include observational methods (Beadle-Brown, Hutchinson and Whelton, 2012), and clarify three areas that are often unclear to staff: reactive strategies, function of behaviour, and teaching strategies (McVilly, et al., 2013). Furthermore, Chiu (2012) found that staff are limited by time constraints to train and to reflect on daily experiences. Staff should be collaborating with individuals to enhance their supports, without the limitation of time and frustration of not fully understanding different strategies. Policies should always be data informed and regularly reviewed to reflect the changing circumstances of the individual (Perez, et al., 2012).

People supporting individuals should have a thorough understanding of behaviours and the language surrounding it, as it shapes the quality of behavioural support provided. A biopsychosocial model highlight the interconnectedness of life events, emotions, and behaviours (Damilton, Sutherland and Iacono, 2005; Esbenson and Benson, 2006). From a family carer's perspective, it is an emotional challenge that they face when the person they care about is exhibiting challenging behaviours (McKenzie et al., 2017). The words and labels used in the literature ranges from a very negative one that emphasizes danger and harm (aggression and violence) to one that values the individual first as a person and does not pathologize them (Baker and Allen, 2012). In emergency or crisis situations, Pryor (2006) suggest a calming method once a problem is identified; to avoid rushing, confrontation, saying no, making demands or startling movements towards the individual. It is usually best to use the individual's name and maintain eye contact, to "work with and for the patient". Instead of using reactive and restrictive strategies, it is suggested that staff should de-escalate, respond to the message being communicated through the behaviour and always mitigate for the non-use of punitive, aversive and/or restrictive strategies.

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3.3.2 Are the results applicable to the population group?

The evidence used to develop this Guiding Principle relates specifically to the provision of behavioural supports for adults and or children with a disability.

3.4 FORMULATION OF RECOMMENDATIONS

3.4.1 What are the recommendations?

The set of Guiding Principles are attached.

3.4.2 Describe the methods used to formulate the recommendations and how final decisions were reached. Specify any areas of disagreement and the methods used to resolve them:

Recommendations were drafted by members of the working group and discussed with stakeholders.

NEXT STEPS:

The Guiding Principles will be discussed with key stakeholders in the country including people with disabilities.

3.5 CONSIDERATION OF BENEFITS AND HARMS

Report the benefits, side effects, and risks that were considered when formulating the recommendations: (may not be required)

3.6 EXTERNAL REVIEW

Report the methodology used to conduct the external review: (discussion points only)

This set of Guiding Principles were reviewed by the HSE Guiding Principles Working Group (chaired by Marie Kehoe-O'Sullivan)

3.7 COMPETING INTERESTS

Confirmation that full group has completed a Declaration of Interest form: ***Yes/*** *No*

For Further Discussion and Consideration:

- Training for frontline staff- how can this be best achieved?

Signed: Marie Kehoe-O'Sullivan Date: 14 July 2020

Lead for Working Group