

Highlights from Rehab Group

Initiatives Supporting the Rights of People with a Disability

Nicola Hardy

Behaviour Therapist (MSc)

Positive Behaviour Support:

Supporting the Rights of People with Disabilities

Nicola Hardy

Behaviour Therapist (MSc)

What is Positive Behaviour Support?

- Established **evidence-based practice** for PWID and behaviour support needs.
- Principles and procedures are drawn from **applied behaviour analysis** (behavioural psych)
- Goals are guided by a focus on the principles of **inclusion, neurodiversity & human rights**
- Implemented as a **multi-faceted model of service delivery** for disability support organisations

What is Positive Behaviour Support?

Focussed on achieving the following outcomes...

1. To improve the person's **quality of life** & help them realise their **rights**
2. To minimize the impact of behavioural expressions of need on the quality of life and rights of others

What is Positive Behaviour Support?

Primary Mechanisms of Change...

1. Creating "Capable Environments"

Creating high quality and person-centred service environments

2. Skills Development

Helping people learn the skills needed to effectively self-advocate, to be as independent as possible & to cope with day-to-day stresses

What is Positive Behaviour Support?

PBS is a tool for rights promotion

- By addressing risks in non-restrictive ways
- By enabling individuals to be more independent and autonomous
- By placing human rights at centre of all decisions in education & social care.

Presentation Overview

Impact of PBS on human rights and quality of life

- Individual level
- Service level
- National level

AN INDIVIDUALS JOURNEY – DAY SERVICE “Brona”

Then

Quality of Life

- Regular incidences of SIB, physical expression of upset directed at staff
- Socially isolated
- Support focussed on avoiding/minimizing risks
- Restricted choices

Rights

- Isolation / seclusion – in a service with only staff
- Restricted access to community experiences
- Loss of access to personal effects

Staff Team

- Focussed on the management & prevention of risk behaviour

Now

Quality of Life

- No incidences of SIB or physical expression of upset directed at staff in 2 years
- Socially included and thriving
- Support focussed on positive risk taking
- Accessing all 12 pillars of ND

Rights

- In a service with 14 others. In a room ratio of 5:2.
- Full community access based on expression of will & preference
- Access to all personal effects

Staff Team

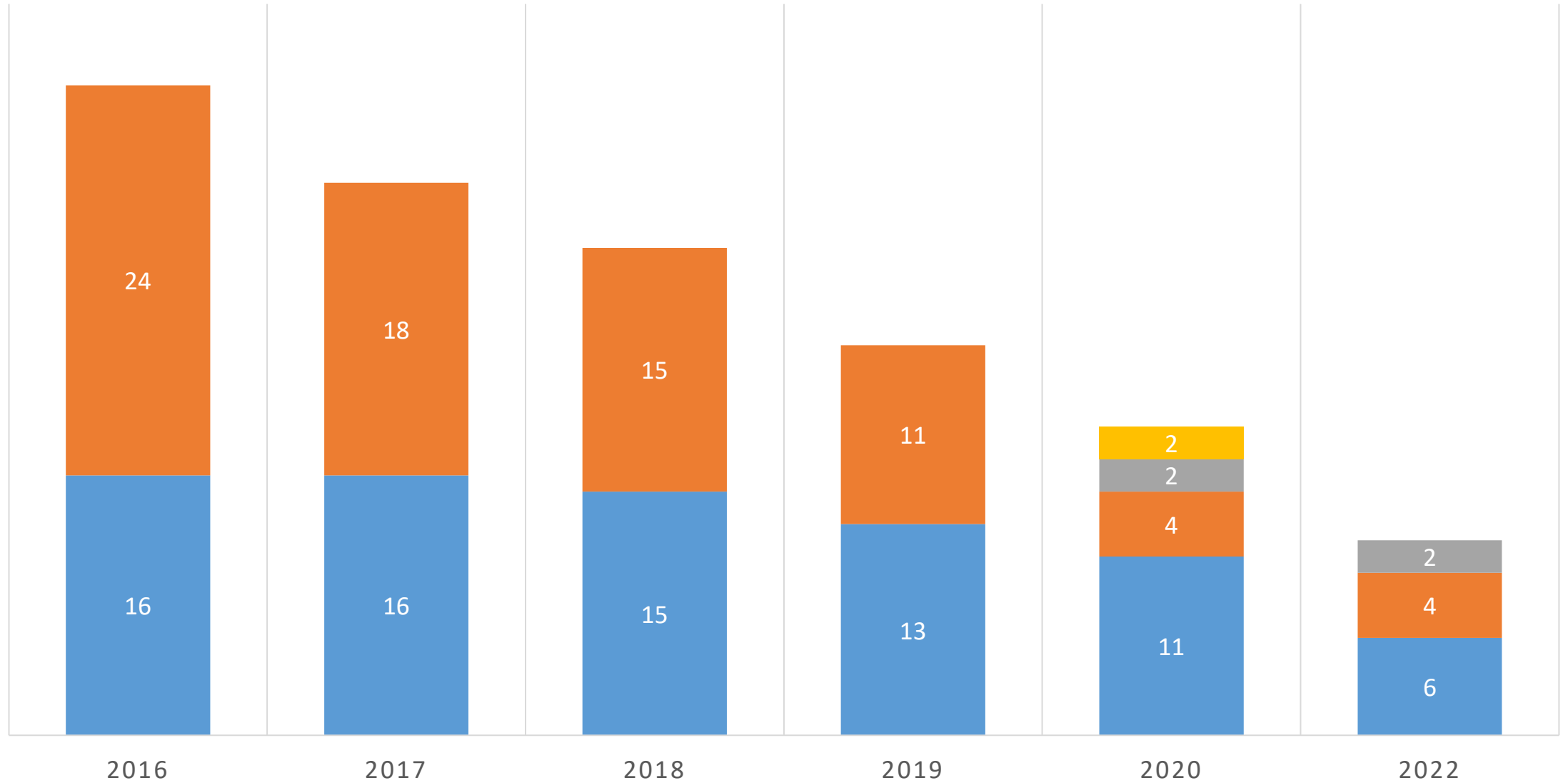
- Proactive, relaxed / supporting though the lenses of QoL, human rights and positive risk taking

A RESIDENTIAL JOURNEY

“Brona” , “Danny”, “Hannah”, “John” & “Monica”

RESTRICTIVE PRACTICE OVERVIEW

■ Medication ■ Other ■ fading out ■ CV19



Then (2016)

Risks

- Significant behavioural risks
- Frequent incidents & injuries
- PBS available but at ineffective intensity
- Risks leading to restrictive measures to manage safety

Rights & Quality of Life

Various rights being restricted e.g.

- Freedom of movement – keypad locks
- Privacy – auditory monitors
- Property – locked kitchen / locked tea press
- Personal autonomy – impacted by the challenges of others / restrictions in choices
- Bodily integrity – helmet/car harness/physical management / PRN
- Being included in the community – supported through a lens of risk management

Now (2022)

Risks

- Significant reduction in behavioural risks
- Very infrequent incidents & injuries
- PBS now available at effective intensity & embedded in service
- People supported to pursue personal goals, become more independent and live a full life.

Rights & Quality of Life

Rights have been reinstated & fully realised e.g.

- Freedom of movement – all keypad locks on doors disabled
- Privacy – auditory monitor only in 1 room for medical purposes only
- Property – no locks on doors/presses
- Personal autonomy – growing independence and expanded choices
- Bodily integrity – helmet being faded out/car harness removed/physical management faded out and removed /PRN reduce
- Being included in the community – supported through a lens of positive risk taking and person lead choice making.

A NATIONAL CHALLENGE
SAFEGUARDING RIGHTS TO BODILY INTEGRITY
DURING THE C19 PANDEMIC

Then

Services

- Under significant pressure to support the roll out of mass testing and vaccinations for people with disabilities living in group settings

Views

- The global pandemic and the crisis it presented superseded the rights of those with disability that presented with challenges around communication and giving consent – viewed as a needs must/for their own good.

Impact on the individuals

- Denied the right to give or refuse consent
- Risk of violation of the human right to bodily integrity

Now

Services

- Supported using a PBS approach to advocate and educate on behalf of those accessing RehabCare services.

Views

- Consent was to be at the forefront of all potential or proposed medial intervention/s relating to the CV19 global pandemic

Impact on the individuals

- Offered individualised skills building support to help understand what was being asked of them.
- Placing their right to bodily integrity at the forefront of all support
- Empowering the individuals right to choice

HOW WAS THIS ACHIEVED ?

A specialised support approach was developed utilising the principle of PBS.

Its aim:

- To empower the service users to give & retract consent
- To learn about what was being asked of them
- To learn about PPE
- To partake in a basic experience in relation to what the test involved

WHAT WE LEARNED AND WHAT WE WANTED TO TRY AND SUPPORT

Then

- Fear of the unknown (what is happening and why)
- fear of an unfamiliar experience (I don't recognize this situation)
- Reaction based fear (I do not like what is happening to me/I don't understand what is happening to me/how can I make it stop).

Now

- I understand what is happening to me
- I recognise this situation/this equipment/this request
- I have some experience of this situation. I am in control. I can stop it at any point. I can say yes, I can try again at a later time if I so wish, or I can say no entirely.

OUTCOME FOR 5 SERVICE USERS IN A RESIDENTIAL SETTING

- The support approach programme was rolled out across 22 learning opportunities.
- The process was broken down into 16 steps.
- Residents were taught to give or retract consent at each step.
- When called for testing, all 5 residents consented to each of the 16 steps.
- The approach was then used for the vaccination programme.
- The approach is being reviewed and adapted for general medical procedures and care.

KEY POINTS - WHAT CAN WE LEARN FROM THESE CASE STUDIES

- Behavioural risks are a significant barrier to quality of life and often lead to the use of rights restrictions for the person and for others (when appropriately resourced alternatives are not available)
- PBS is an effective way to address behavioural risks
- PBS is a resource intensive intervention and is often not resourced adequately. When it is, significant and meaningful positive changes can be achieved.

KEY POINTS - WHAT CAN WE LEARN FROM THESE CASE STUDIES

- PBS also has value outside of situations of behavioural risk e.g., in supporting autonomy, independence, quality of life and rights.
- People who receive PBS value this input.

WHAT DO THE ABOVE CASES TELL US ABOUT POSITIVE BEHAVIOUR SUPPORT?

- It tells us that PBS, when used effectively, can have significant impact on the promotion of human rights for those with disability.
- It demonstrates that with the right level of expertise and time allocation, those with disability can be supported to communicate their will and preferences and learn about and understand processes through individualised, person centred approaches.
- It highlights that, no matter the complexities surrounding the direct application of the capacity act, PBS can play an active and effective role in ensuring it reaches those that it directly impacts in meaningful ways.

FEEDBACK FROM THOSE UTILISING THE PBS STRATEGIES IN THE CASE EXAMPLES PROVIDED

“PBS has definitely led to improvements in the QOL for those attending our services. It has made us look at the way we do things and supports us to explore new less restrictive ways” CC. Programme Supervisor.

The PBS approach “supports staff extremely well with person centred programmes to ensure all service users' needs are met”. JR. Programme Facilitator.

STAFF

“PBS improves the QOL for service users as it empowers them and the people in their circle of support to confidently participate in life” AS. Programme facilitator.

As a member of staff who often can deal with behaviours of concern, I always feel supported by the PBS strategies given by the BT and the advice that they give to me regarding supporting service users to have a excellent QOL'. NW. Programme facilitator.

FEEDBACK FROM THOSE SUPPORTED THROUGH PBS STRATEGIES

“Thank you for helping me with money management. I am getting more independent now”. Service User. Rehabcare day service.

SERVICE USERS

“I am learning to make my own choices. I am doing more. I feel happier. I like having a BT to support me”. Service User. Rehabcare day service.



FEEDBACK FROM THOSE UTILISING THE PBS STRATEGIES

THE WORDS OF A MOTHER

“the approach just works so well for him. He is doing things I never thought possible; swimming, horse riding, shopping and learning to make his own lunch. He is getting to make choices and is supported to be heard. I used to go to bed worried for his future, now I go to bed excited for his future”