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Improving Quality of Life - Introducing the first Psychologically Informed Environment (PIE) for adults with autism and intellectual disabilities

Dr Rachel Worthington
Director of Interventions
MHC Social Care

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Aims

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- What is a PIE?
- How does PIE work for people with Autism and ID at MHC?
- How effective is PIE?
- What is the future?

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Who are we?

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- Mental Health Care UK (MHC) Social Care provide care to individuals with learning disabilities, behaviours that challenge, mental health issues, and autism.
- We have homes for adults in North Wales and the North West of England
- Community-based living accommodation ranges from single person to group living arrangements. Each home within Llangwyfan offers a specialist service for people with learning disabilities and autism.

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What is a PIE?

- The Psychologically Informed Environment (PIE) concept was described as aiming to '*enable clients to make changes in their lives*' (Keats et al., 2012), which can be detailed in '*measurable changes in behaviours or emotions*'.
- A psychologically informed environment, or 'PIE', is a place or a service in which the overall approach and the day-to-day running have been consciously designed to take into account the psychological and emotional needs of people being supported.

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What is PIE not?

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- It is not a ‘treatment’
- It is not just about training
- It is not something psychology ‘do’
- It is not the latest craze or fancy word

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PIE is….

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- a consciously adapted environment in which organizational decisions, behaviour, and culture can be informed and planned on the basis of psychological thinking in order to address the psychological and emotional needs of the people within it.
- ‘The environment’ includes all the external conditions, covering both individual and social relationships
- A PIE aims to facilitates learning and growth
- Creating a psychological integrated environment involving all staff and not just ‘psychology’ or just ‘front-line staff’ only.
- EVERYONE THINKS and ACTS in a psychologically informed way

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How is PIE different?

CHANGES DON'T HAPPEN ONCE A WEEK IN A THERAPY ROOM….

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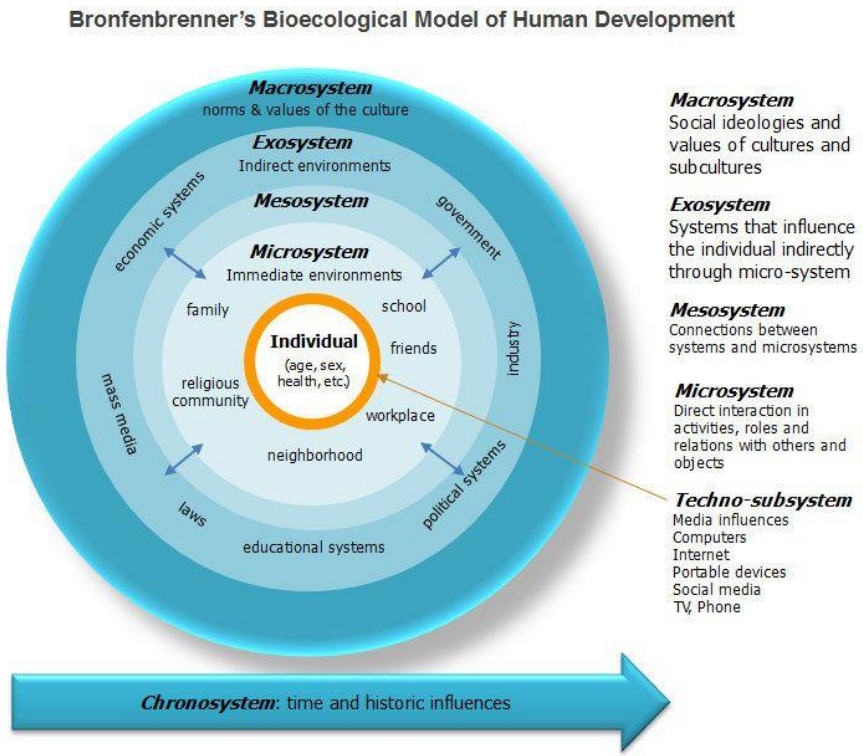
Change happens best when it comes from everywhere…



- The individual
- Support Staff
- Families and friends
- Senior Managers
- SALT, Maintenance, Admin, Training, HR, GP, Dentist, Teacher, Massage therapist..
- The community
- We are all have an equal role

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Why would we use a PIE approach for people with Autism and Intellectual Disabilities?

Psychologically Informed Environments have been used successfully for clients with a range of needs because research finds they provide:

- consistent and reliable relationships
- an environment where the people being supported can feel heard
- support for individuals to develop practical and psychosocial skills
- wellbeing, independence and choice
- reflective interactions between staff and residents where staff are 'mindful' of every interaction (both verbal and non-verbal) they have and how this could impact on the person they are supporting
- organisational decisions that are made on the best interest of the individual
- shared and thoughtful learning from experience
- Reductions in staff burnout

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What is a PIE made up of?

When developing a PIE approach (Keats et al., 2012) identified five key areas:

- 1. Developing a psychological framework
- 2. The physical environment and social spaces
- 3. Staff training and support
- 4. Managing relationships
- 5. Evaluation of outcomes

What does this look like at MHC?

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1. Developing a psychological framework

- Positive Psychology - all humans have fundamental human needs and the role of staff is to facilitate the person to meet those needs in a way that makes the person happy and does not cause themselves or others harm – focus on human needs NOT ‘reducing autism’ or ‘reducing’ disabilities or reducing behaviours of concern.
- How?

- Positive Behavioural Support with a truly <u>proactive</u> human needs focus
- Active Support integrated with Person Centred Planning
- Reflective Practice
- Action research

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Quality of life (QOL) defined

World Health Organisation (WHO) identifies that QOL can be defined as:

*"A state of complete **physical**, **mental**, and **social well-being** not merely the absence of disease"*

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Subjective Well-Being and Happiness

Seligman's PERMA model

- The PERMA model was designed with **five** core elements of psychological well-being and happiness which help people reach a life of fulfilment, happiness, and meaning.

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Origins of Active Support

- Person Centred Active Support originated in the United Kingdom in the early 1960s.
- At this time, disengagement of people with intellectual disability was a major problem.
- In many services people spent most of their day doing nothing – disengaged – waiting for something to happen.

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The Hotel Model

- Residents are spectators in their own lives.
- Staff feel like ‘glorified domestics’.

- In **active support** people **participate** in everyday activities with **support**

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Person-centred active support

- Providing **enough help** to enable people to **participate** successfully in meaningful activities and relationships…
- …so that people gain more **control over their lives**, gain more **independence** and become more **included** as a valued member of their community
- …**irrespective** of degree of intellectual disability or presence of extra problems.

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Active Support and PBS

Not an ‘intervention’ for challenging behaviour…

BUT

Active support can work as a **proactive strategy** and can help reduce behaviours of concern that impact on the quality of people’s lives.

McGill & Toogood, 1994; Jones et al. 2013).

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2. The physical environment and social spaces

- Environmental Assessment
- Compatibility Assessment
- Sensory Assessment
- Quality of Life Assessment

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Improving the environment

- For each person a positive environment checklist was completed which evaluated the quality of the: physical setting; social setting; activities; scheduling and predictability; and communication.
- Each person also had a sensory assessment which identified their personal sensory needs and preferences. This enabled the environment to be adapted to meet their needs. For example, those with a low neurological threshold for noise would not be placed with a person who was noisy or those with a high activity threshold could be placed in larger homes with long corridors and bigger outdoor gardens.

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Social spaces

- In terms of social spaces, a range of activities were provided both indoor and outdoor in the 'Highfield Hub' and the Woodlands Project
- National Open College Network (NOCN) accredited courses (e.g. Maths and English; Independent Living Skills qualifications; Skills for Education, Training and Personal Development).
- Non-accredited activities are also available such as art and crafts, archery, sports activities, mosaics, music/singing, walking groups, news discussion groups, puzzles, sewing and needlecrafts and individually focussed activities through a drop-in centre.
- Outdoor learning space including woodland crafts, sensory activities and relaxation areas and nature activities.
- Sports - rugby
- Providing spaces where people who may have dysregulated sensory systems would have the opportunity to learn, as it was recognised that not all people may suit learning in a classroom, and as such they could learn outside, run around, utilise specially ma outdoor sensory equipment and not be excluded from personal development.

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Hit Me

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Who wants to learn in a classroom anyway…

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3. Staff training and support

- Positive Behaviour Support (PBS)
- Systemic PBS – support workers write the plans
- Autism
- Active Support
- Mental Health, Learning Disability, Person Centred Planning.
- Bespoke Training : Pathological demand Avoidance, Acquired Brain Injury, and Personality Disorder Training
- Consultancy – ad hoc training, webinars, research, awareness days
- Posters – putting research into practice

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"Stop Talking!

I can see too many red balloons…"

"she thought she was helping, trying to talk to me to calm me down, but all I could see was huge red balloon shapes coming out of her mouth one after the other. I just wanted it to stop hurting my eyes, I didn't mean to hit her…"

Synaesthesia [pronounced: sin-as-thee-see-a] is known as the 'extra ability'. A person with synaesthesia usually has two (or more) perceptions of the <u>same</u> stimulus.
So, they may *see* spoken words, as well as hear them…

For more information on Synaesthesia, or other sensory issues please contact the PBS Team

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Increasing knowledge

- Set up a research and ethics committee which supported staff development through both undertaking research in the field and also sharing current research with staff to support their development.
- Based on the latest research, posters were developed and designed by the PBS team explaining complex research in an easy to understand and practical way for staff to implement more easily.
- For example, posters outlining the negative effects of inactivity on behaviours of concern were designed and put in simple terms so that staff could understand the benefits of encouraging the people they support to be more active.

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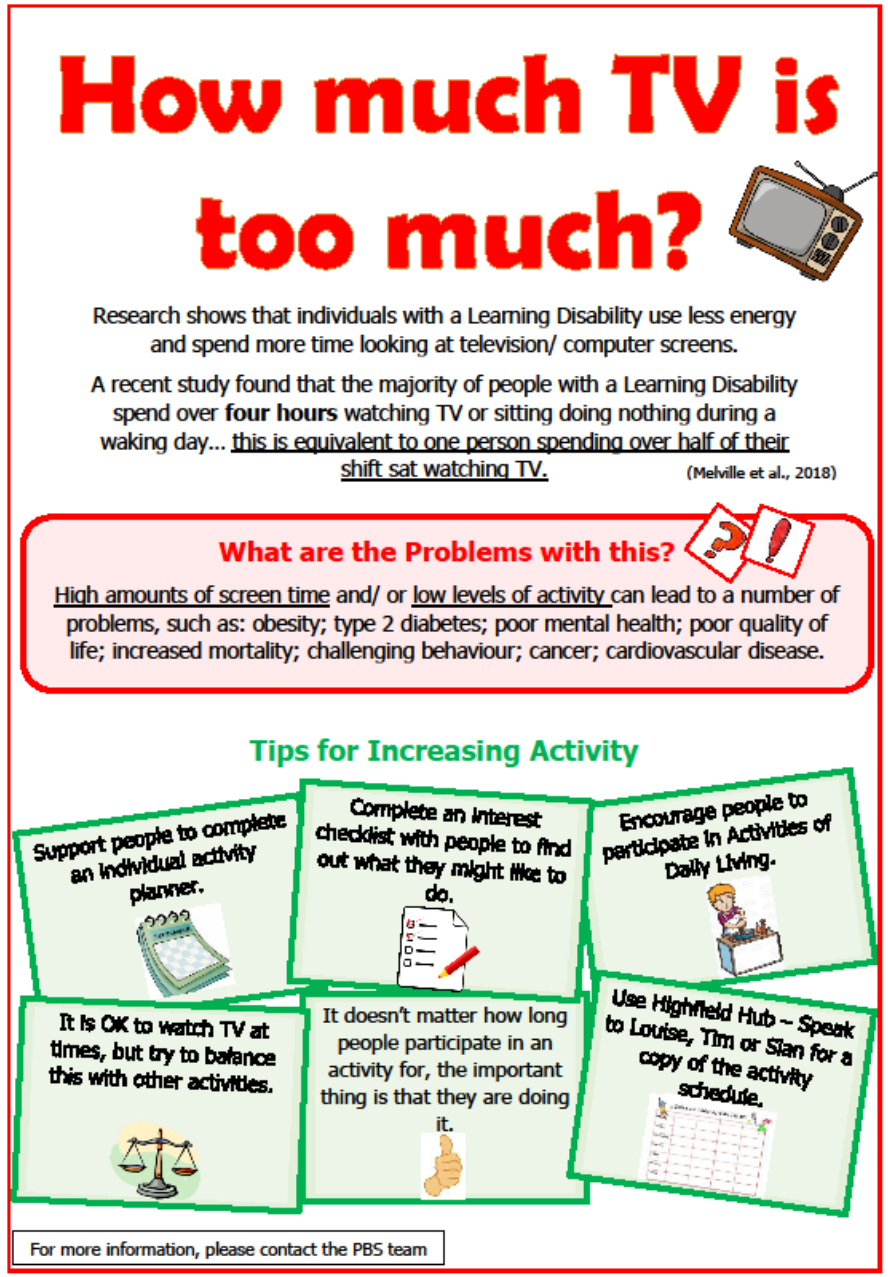
- Posters



How much TV is too much?

Research shows that individuals with a Learning Disability use less energy and spend more time looking at television/ computer screens.

A recent study found that the majority of people with a Learning Disability spend over **four hours** watching TV or sitting doing nothing during a waking day... this is equivalent to one person spending over half of their shift sat watching TV. (Melville et al., 2018)

What are the Problems with this?

High amounts of screen time and/ or low levels of activity can lead to a number of problems, such as: obesity; type 2 diabetes; poor mental health; poor quality of life; increased mortality; challenging behaviour; cancer; cardiovascular disease.

Tips for Increasing Activity

Support people to complete an individual activity planner.

Complete an interest checklist with people to find out what they might like to do.

Encourage people to participate in Activities of Daily Living.

It is OK to watch TV at times, but try to balance this with other activities.

It doesn't matter how long people participate in an activity for, the important thing is that they are doing it.

Use Highfield Hub – Speak to Louise, Tim or Stan for a copy of the activity schedule.

For more information, please contact the PBS team

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Increasing skills

- In order to implement Active Support on a daily basis documentation was designed for staff to complete which identified personalised target goals for each person based on their assessment of daily living skills (ADL's)
- Each person was assessed using tools measuring their quality of life which also informed goals

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Increasing skills

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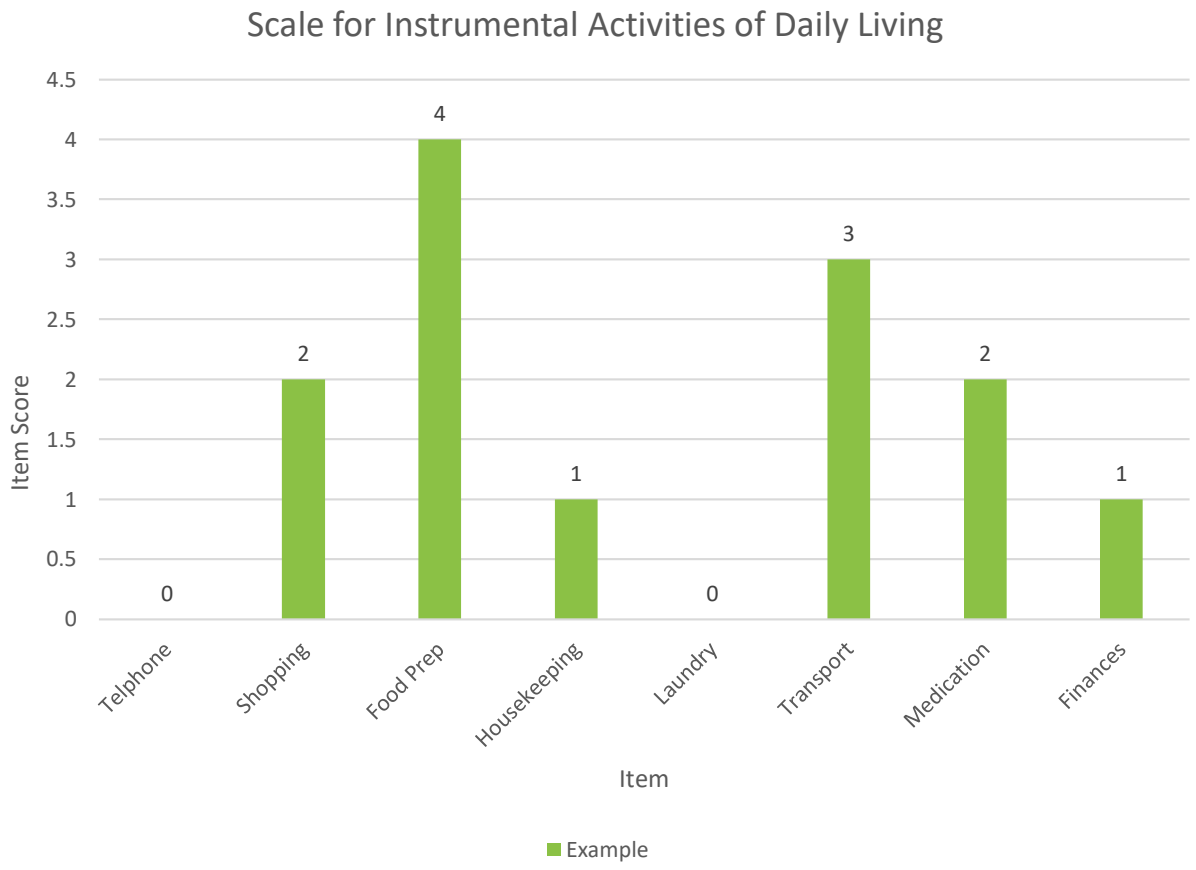

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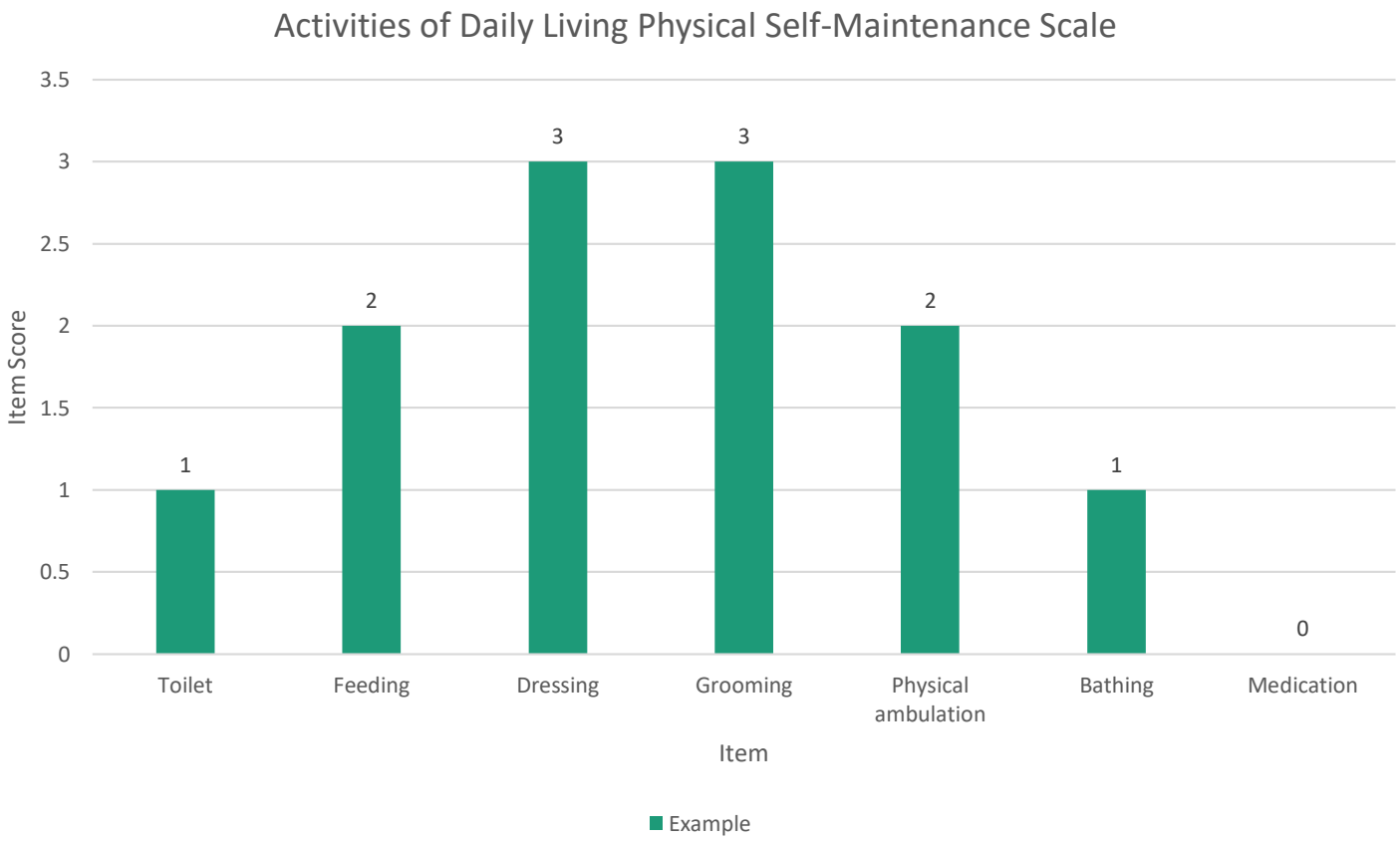
Increasing Skills



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Increasing Skills

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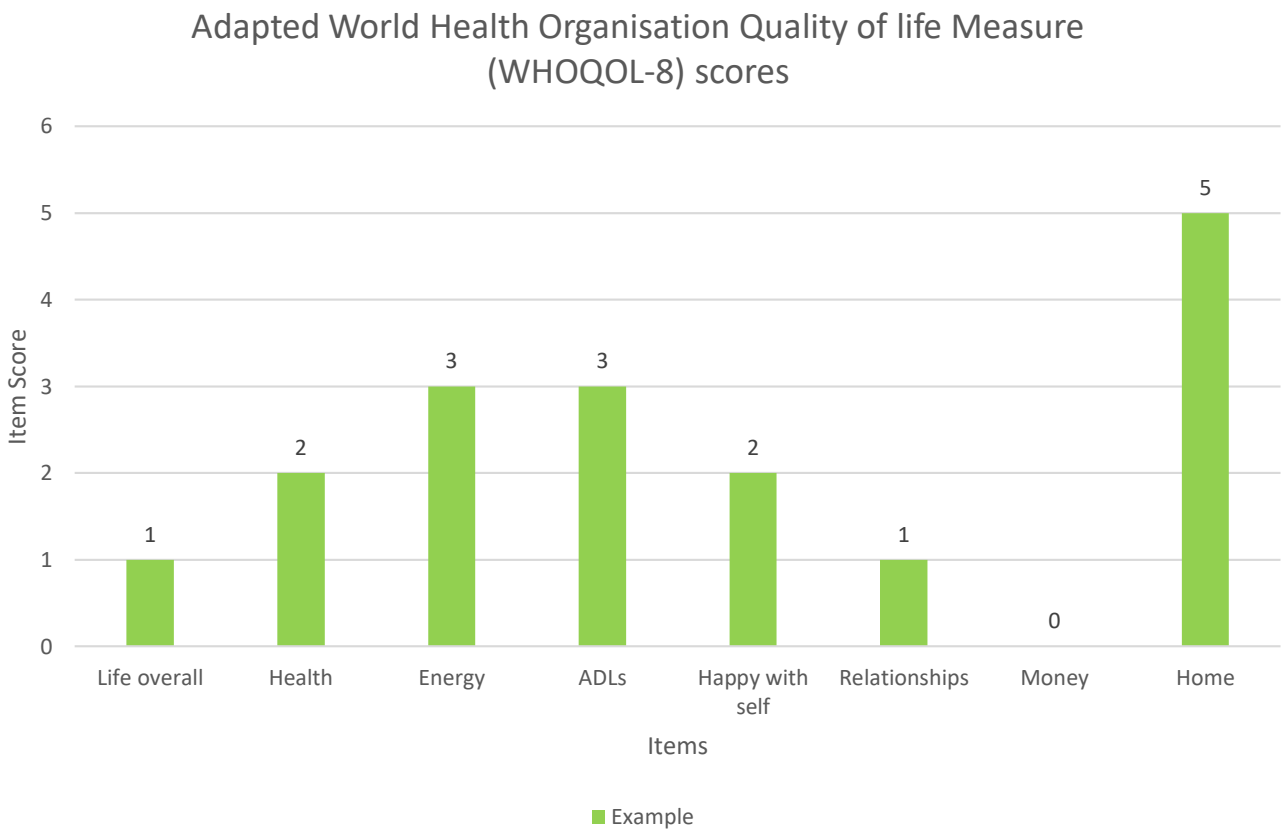

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ADL and QOL scoring LD ASD - Excel

Name	
D.O.B	
Home	
Date of Assessment	
Assessment compleed by	
Job Title	

Totals		
Catgories	Score	Mean
MANS LD		
Getting the most out of life	12	4
Feeling good	18	3.6
Feeling wanted	13	3.25
Safety	19	3.8

MANS-LD Easy Read Prospective with WHOQOL				
		MANS LD	Answer (1-5)	Score
1		Basic needs are met	4	4
2	R	Other people try to hurt me	2	4
3	R	Feel like hurting other people	1	5
4	R	Feel like deliberately hurting self	1	5
5		happy with how I spend time	1	1
6		Happy with where I live	4	4
7		Happy with health	4	4
8		Get on well with people I know	4	4
9		Make and Keep friends	1	1
10		Feel accepted by other people	4	4
11		Happy about boyfriends or girlfriends	4	4
12		Feel good about myself	4	4
13		Feel confident	3	3
14		I am achieving what I want to	4	4
15		I feel other people respect me	3	3
16		I feel I respect other people	4	4
17		I feel like life is worthwhile	4	4
18		I fele like I accept who I am	4	4
19		I feel like I am being everything I can be	4	4

WHOQOL-8			Answer (1-5)	Score
1	N	Overall, do you feel lyour life is...	2	2
2	N	How happy are you with your health?	2	2

Key- MANS-LD
Answer
Hardly ever
Not very often
About medium
Most of the time
Nearly Always

WHOQOL-8
Answer
Very good/ very

IADLs | ADLs | MANS-LD WHOQOL-8

READY 85%

12:43 05/03/2018

Increasing skills

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Active Support Goals

Look at the graphs above and discuss with the individual (where appropriate) the areas they want to improve, or the areas that have been highlighted as needing improvement. Use this to set goals to focus on in the month ahead.

Goals should be **SMART-ER: S**pecific, **M**easurable, **A**chievable, **R**ealistic, **T**ime bound – **E**valuated, **R**eviewed

Area identified for improvement	Specific Goal
1. Handling Money	1. Identify correct change for the bus ride in to Denbigh
2. Laundry (and ADLs)	2. Complete laundry twice per week
3. Food Preparation and Shopping (self-requested goal)	3. Prepare simple lunch using the hob and grill:

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Daily Participation Record

*** Levels of support Key: A-** Ask: **I –** Instruct: **P-** Prompt: **S-**Show: **H/H:** Hand over Hand (Guide)

Self-care	Level of Support*	Offered/ Accepted/ Refused	Hobbies	Level of Support	Offered/ Accepted/ Refused
Showered Self			Gardening		
Shampooed Hair			Watching TV		
Dried Self			Listening to Radio		
Dried Hair			Listening to music		
Combed Hair			Using Computer		
Brushed Teeth			Reading		
Meals			Playing games		
Prepared breakfast			In house Activities (please state):		
Prepared lunch					
Prepared dinner			Family & Friends		
Laid Table			Visit from family		
Made cup of tea/coffee			Visit from friend		
Cleared Table			Out with family/friend		
Clearing up after meals			Visiting other people		
Put dishes/cutlery away			Community Activities		
Loaded dishwasher			Pub		
Emptied dishwasher			Café		
Wiped kitchen surfaces			Restaurant		
Wiped table			Cinema/Theatre		
Tidying & Cleaning			Bank/Post Office		
Dusted bedroom			Library/Museum/Gallery		
Mopped floors			Going for a walk		
Vacuumed			Bowling		
Cleaned bath/shower			Golf		
Made bed			Spectator at event		
Laundry			Swimming		
Used washing machine			Gym		
Hung clothes out			Fitness class (specify)		
Used tumble dryer			College		
Ironed clothes			Other (please state):		
Put clothes away					
Shopping					
Made shopping list					
Small local shop					
Big supermarket shop					
Put shopping away					

Opportunity Plans

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The opportunity plan outlines the goals the individual is working towards, the expected outcomes and how these will be achieved. A 'Task Analysis' may also be required for some activities, to ensure that all staff are consistent in their approach when supporting the individual.

Active Support monthly goal: (e.g. to learn to count money to catch the bus independently)	**Is there a task analysis for this?**	**Y**	**N**
	If so, has this been followed?	Y	N
What opportunity has the person had to work on their Active Support goals?:			
What level of support was required: A - Ask: I – Instruct: P- Prompt: S-Show: H/H: Hand over Hand (Guide) [circle as appropriate] **Details:**			

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4. Managing relationships

- Proactive PBS plan focussing on improving quality of life, understanding the function of behaviour and with the aim of achieving the human need in ways that don't cause the person a problem– teaching skills, relaxation, mindfulness, managing emotions, communicating needs, social stories, education
- Quality of Life assessments to guide support staff selection (staff matching, PCP)
- Positive risk assessment to maximise community engagement
- Research – what are the skills that are helpful when supporting someone with autism?
- Recruitment tool development – Values based
- Compatibility Tool – used to inform decision making and support

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Living Well Together

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Apps New Tab

Living Well Together

Add Data

Compare

Update Person

Administration

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Type here to search

ENG 09:52 29/06/2017

Living Well Together

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Apps New Tab

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Collecting Data for 'Homer Simpson'

Are you messy?

Yes

Sometimes

No

Type here to search

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Living Well Together

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Apps New Tab

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Collecting Data for 'Homer Simpson'

How would you feel if you lived with someone who did the same thing at the same time every day?

- Good
- Don't Mind
- Bad

What would you do if you lived with someone who did the same thing at the same time every day?

- Hit Out
- Shout
- Walk Away
- Talk to Staff
- Nothing

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Collecting Data for 'Mary Poppins'

How would you feel if you lived with someone who was messy?

- Good
- Don't Mind
- Bad

What would you do if you lived with someone who was messy?

- Hit Out
- Shout
- Walk Away
- Talk to Staff
- Nothing

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Collecting Data for 'Mary Poppins'

How would you feel if you lived with someone who was noisy?

- Good
- Don't Mind
- Bad

What would you do if you lived with someone who was noisy?

- Hit Out
- Shout
- Walk Away
- Talk to Staff
- Nothing

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Comparing Homer Simpson and Mary Poppins

Compatibility:

Homer Simpson will feel good because: Mary Poppins is clean and tidy.
Mary Poppins does the washing up.

Homer Simpson will feel bad because: Mary Poppins does the same thing at the same time every day. Homer Simpson will walk away.

Mary Poppins will feel bad because: Homer Simpson is messy.
Homer Simpson is noisy.
Mary Poppins will shout.
Mary Poppins will hit out.

Email Report

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Living Well Together | Untitled

about:blank

Apps | New Tab

Write: Compatibility for Homer Simpson and Mary Poppins

File Edit View Insert Format Options Tools Help

Send | Spelling | Attach | Security | Save

From: Rachel Worthington <rachel.worthington@zen.co.uk> rachel.worthington@zen.co.uk

To: rachel.worthington@mhc-uk.com.com

Subject: Compatibility for Homer Simpson and Mary Poppins

Body Text | Variable Width

Homer Simpson will feel good because:
Mary Poppins is clean and tidy
Mary Poppins does the washing up

Homer Simpson will feel bad because Mary Poppins does the same thing at the same time every day. Homer Simpson will walk away.

Mary Poppins will feel bad because:
Homer Simpson is messy. Mary Poppins will shout.
Homer Simpson is noisy. Mary Poppins will hit out.

Recommendations:

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5. Evaluation of outcomes

- 6 monthly review to explore individual PBS plans, Quality of Life measures and goals and to set goals for Active Support for the next 6 months. Thus, individual outcomes are integrated into the plan and regularly reviewed
- Clinical Audit and Effectiveness
- Research Committee Supporting internal and external research

- University input
- Peer reviewed publications
- Ongoing research to inform practice (Aggression, Self-Injury, Staff Skills etc)

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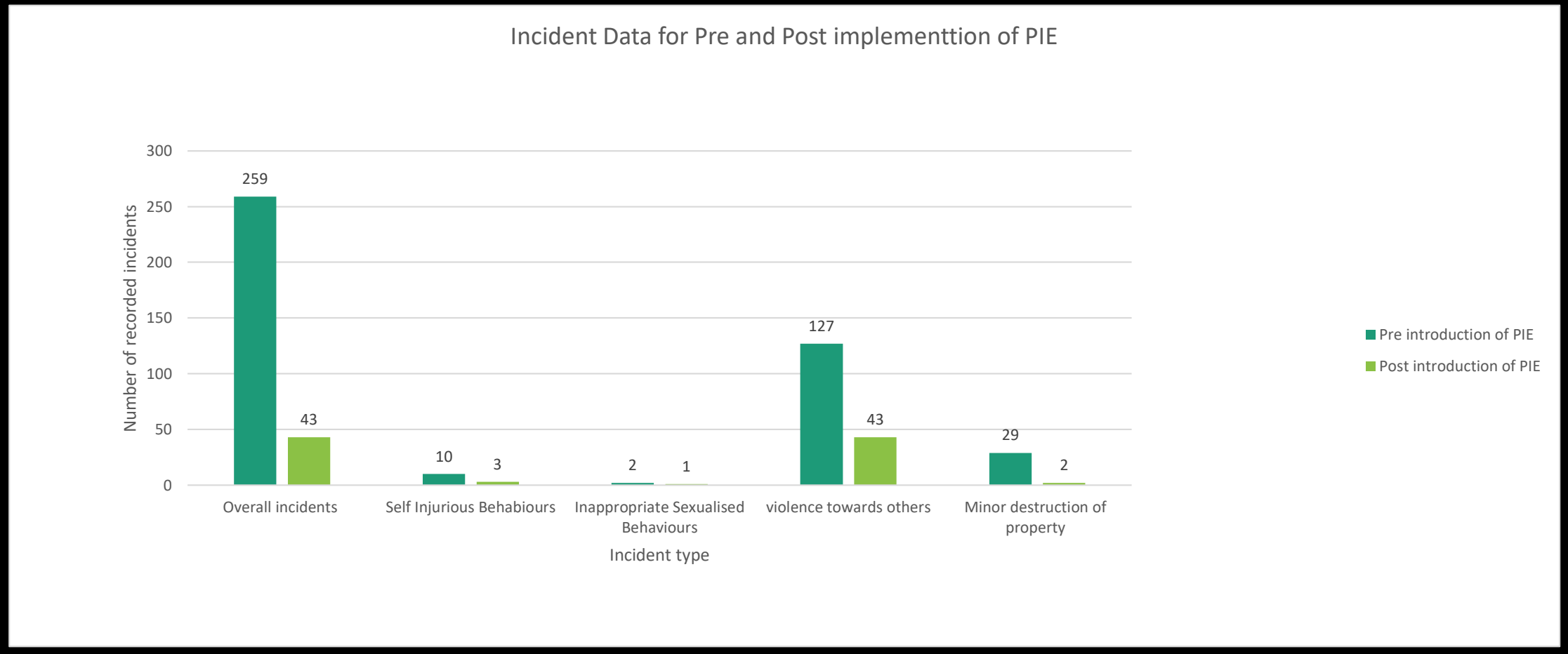
Effectiveness



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Effectiveness?

- Since the implementation of the PIE at the services in Llangwyfan there has been a **reduction in overall incidents**.
- In one service alone the number of overall recorded incidents has **reduced by 85.4%.**
- The number of incidents requiring or resulting in the use of **physical interventions** has **reduced by 89%;**
- **Self-injurious behaviour is down by 70%;**
- **Minor destruction of property has dropped by 93%;**
- **Physical violence towards another has reduced by 66%;**
- **Sexualised behaviours** have seen a **reduction of 50%**.
- Nearly 150 PBS plans have been completed – WE ARE ALL PSYCHOLOGISTS!

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Outcomes

- 248 staff have undertaken training in Active Support
- 266 members of staff, which includes Executive Management, support staff, Deputy Managers and Home Managers have participated in regular Reflective Practice
- Activity engagement hours in 'Highfield Hub' have doubled. There has also been an increase of 62% in the number of 1:1 sessions being facilitated (where individuals engage with the activities team in person specific activities on a 1:1 basis), an increase of 86% in engagement in 'English' and an increase of 97% of hours engaged in maths sessions. This has also seen those who were previously considered to be unlikely to engage in such sessions, working towards achieving NOCN qualifications in Maths and English

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Outcomes

- In a recent award ceremony for people, one person with Level 3 autism and a moderate intellectual disability received a certificate in English because staff had been able to engage him in education sessions and learned that he knew a large number of words they did not realise he had.
- Half of the choir consisted of people regarded as ‘non-verbal’, that is, although they do not use verbal communication they were able to experience enjoyment in singing.
- Over 30 people attended the ceremony to receive awards where previously staff would have felt reluctant to bring people assuming ‘they will never cope’ in such an environment and yet they modelled how having positive expectations could have positive outcomes.

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Outcomes

- Following the implementation of the revised 'daily diaries' staff have been able to better capture information specific to the individual's engagement in activities of daily living, as well as increasing focus on SMART goals for improving quality of life and encouraging independence in areas it has been identified the individuals struggles.
- One Home Manager stated "*the new daily records are really helpful, just looking in one person we support, their' diary for this morning, I can already see 6 great examples of active support which may not have been captured previously. This person also came to see me, really excited that they had made their own cheese sandwich for lunch, it's great to see".*
- A Team Leader supporting individuals in another home stated "*the documentation is really helpful, so far we have been able to identify patterns where one individual does not complete his laundry- this isn't because he is unable to necessarily, but more because he is not consistently offered th opportunity. We are now going to look at the way we support him, and that we are offering his this opportunity, with the right staff support".*

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Effectiveness… Case Study

Michael (name changed) has autism and a learning disability. He was housed with 4 other residents and supported by staff 24 hours a day. He was engaging in multiple acts of aggression on a daily basis. Staff burnout was high with staff wanting to leave because although they wanted to support Michael they were being physically injured on a regular basis. His family were frightened of the harm he might cause to others

Options?

- Serve notice?
- PIE?

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PIE approach for Michael

- Reflective practice – Staff were able to identify who Michael did not hit as well as who he did. They identified that people with a certain pitch and tone of voice were at greater risk and people who were more direct in their speech were less likely.
- Sensory profile – it took a lot to stimulate touch, vision and movement processing and Michael actively seeks this stimuli for all 3 senses; it does not take much to stimulate his auditory processing and he avoids or self regulates this stimuli
- Environmental Assessment –The staff completed an environment assessment and noticed that the staff often gathered in a circular space but this was close to Michael's room and maybe he could hear them and did not like it

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PIE APPROACH for Michael

- SALT – the SALT report identified that Michael could understand 2-3 words at a time. This was shared with staff in reflective practice. Staff then practiced how to give instructions. They reflected on their response to increases in Michael's agitation (reading entries of how they 'verbally supported' him when he was 'anxious')
- Training – staff took part in sensory awareness and autism training. They realised by 'verbally' supporting Michael they were overloading him. They also realised that he avoids loud noises and that when some staff shouted out if he hurt or surprised them when he was agitated this added to his distress. The staff designed some posters to help remember about the senses and to help all staff understand sensory needs. These were placed ALL over the Llangwyfan services, from the admin buildings, to toilet doors, kitchens, cleaning cupboards and staff notice boards

"OUCH!
The noisy fridge is hurting me!"

"When I was little, loud noises were…a problem, often feeling like a dentist's drill hitting a nerve. They actually caused pain. I was scared to death of balloons popping, because the sound was like an explosion in my ear. Minor noises that most people can tune out drove me to distraction" (Temple Grandin, 2006).

Hyperhearing- hearing 'inaudible' sounds. Many of the people we support find many daily noises physically painful. These are often noises we don't even notice- the 'whirring' of the fridge, the 'humming' of the fan…

For more information on 'hyperhearing', or other sensory issues please contact the Psychology Team at Highfield Park

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PIE Approach for Michael

Positive outcomes for people

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- Staff realised that Michael's aggression was him attempting to regulate his CNS. He would do this when he did not have enough stimulus. For example, his sensory assessment noted that it took a lot to stimulate his touch, visual and movement processing and Michael was actively seeking this stimuli for all 3 senses. By engaging in aggression he received touch input but it was just in a way that caused himself and others a problem
- Staff completed a quality of life assessment and looked at movement activities he could engage in to help him regulate his CNS. He liked skateboarding and he was supported by staff who had an interest in this using staff matching tools.
- They worked with the staff in the Hub and Woodland Project to explore ways he could 'move' outdoors – doing long walks and physical activities

Positive outcomes for people

MHC

PIE approach with Michael

- Staff worked with the placements team to ensure new admissions to the home did not have a high auditory sensory profile (i.e. if they made a lot of noise)
- The Management Team supported this and ensured that financial pressures to take new people in the homes did NOT come before the needs of individuals in the homes. They also worked with the finance team to explore better sensory provisions – approving the Woodlands Project and exploring investment in sensory equipment
- Staff also worked with the estates team to look at how they could reduce the noise in Michael's room. The estates team also made changes to the sensory room to modify the sound equipment, and the staff made sure no fire alarm testing happened without Michael knowing first

Positive outcomes for people

MHC

PIE approach with Michael

- Staff completed Active Support Training and looked at ways they could reduce Michael's boredom by getting him more engaged. He became involved in cooking (he liked kneading dough as it stimulated his senses) and he also liked doing the hoovering which stimulated his movement
- We undertook research to explore what skills were helpful when supporting people with autism as it seemed that high expressed emotion in staff was unhelpful – we wanted to test this to help with staff selection in the future
- We are working with HR to incorporate our findings into staff selection and recruitment
- We also undertook research to look at what might predict aggression in people with autism to try and see if we could use this to inform interventions and anticipate what levels of support people might need

Positive outcomes for people

MHC

PIE Approach for Michael

- Incidents of aggression reduced by 87%
- But more importantly Michael's quality of life improved and his engagement in activities that were meaningful to him increased significantly
- Staff felt more confident working with him
- His family feel happier and less scared about what his future might hold

Positive outcomes for people

MHC

PIE - Implications and the future

- PIE provides a cost effective approach to providing psychologically informed approaches in the community
- PIE improved quality of life and reduced incidents of aggression
- Initial outcome data indicates that PIE helps both the individuals we support and the staff supporting those individuals
- Continue research and development
- These are just some of the ways that PIE is implemented at our services. If you would like more information about PIE and how this works in practice then please come and have a look at our stand to see the research and tools we have developed or contact:
- Rachel.Worthington@mhc-uk.com