A decorative graphic on the left side of the slide, featuring three overlapping organic shapes: a light blue shape at the top left, a green shape in the middle, and a yellow shape at the bottom right. The shapes are set against a dark blue background.

Using acceptance-based
interventions to promote the well-
being of caregivers of young people
with intellectual and developmental
disabilities.

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Our service

- Child and Adolescent Mental Health Service (CAMHS) within Central and North West London (CNWL) NHS Trust in the UK.
- We work with children and young people up to the age of 18 who attend special schools.
- They must have a diagnosis of an intellectual disability AND behaviour that challenges (Emerson, 1995; Royal College of Psychiatrists, 2007) OR mental health needs.
- The majority of the young people we support also have a diagnosis of ASD.



Our approach

- We work within the Positive Behaviour Support (PBS) framework (Gore et al., 2013), a functional, constructive and effective way of delivering support that is valued and acceptable to service recipients (Kincaid et al, 2016; Reid and Nelson, 2002). It builds upon developments in ABA.
- We conduct a comprehensive behavioural assessment aiming to identify the function (purpose) the behaviour serves for the individual.
- Following the assessment we meet with the person's significant others (school and family) and develop a Behaviour Support Plan that outlines the interventions.
- We offer support and training to everyone involved for the implementation of the plan.
- Our aim is to improve Quality of Life, reduce behaviours that challenge, and teach socially appropriate, and functionally equivalent skills.



Challenges

- Parents of children with intellectual disabilities experience high levels of stress (Hastings, 2009).
- Higher levels of stress can significantly impact parents' ability to respond effectively to behaviours that challenge, and accordingly reduce the success of behavioural interventions (Gould, et al. 2017).
- Professionals place demands on parents which they might not be ready to meet.
- Often we see families at times of 'crisis'.
- How do we support caregivers' well-being in order to improve treatment adherence and engagement?



Our workshops

- They were based on the work developed by Reid et, al. (2015).
- Two 4h workshops experiential in nature held 1 week apart.
- Facilitated by a qualified clinician and an assistant psychologist.
- Participants had to attend both workshops.
- Participation in the workshops was voluntary and didn't affect the care provided by the team.
- The workshops were structured around 5 key concepts of ACT including acceptance, living in our thoughts and alternatives/defusion, being present, values and committed actions.
- A range of exercises, metaphors and discussions surrounded these concepts.



Participants

- 18 caregivers (16 female, 2 male) attended only the first workshop.
- 12 caregivers (67%, 11 female and 1 male) completed both workshops.
- All cared for young people who were seen by a CAMHS LD team, had diagnosed intellectual disabilities and presented with behaviours that challenge (varied from low to high risk behaviours).
- Participants speaking English was an inclusion criteria (although 1:1 sessions can be offered with an interpreter).



Outcome measures

- Parental Psychological Acceptance scale (MacDonald, et. al. 2010)
- Goal based outcome
- Qualitative feedback through a semi-structured interview



Parental Psychological Acceptance

- Designed to be used as a process measure in ACT research and generally in any situation where researchers / practitioners are interested in “acceptance”.
- 8 questions that participants are asked to score from 1 - 7 (statement is never true to always true).
- Completed at *three* points of time; before the first workshop, before the second workshop and 3-6 weeks after the end of the second workshop.

Below you will find a list of statements about you and your child with intellectual disability. Please rate how true each statement is for you by circling a number next to it. Use the scale to make your choice.

	Never true	Very seldom true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
1. It's OK if I remember some of the difficult times I've had parenting my child with intellectual disability.	1	2	3	4	5	6	7
2. I'm afraid of my feelings about my child with intellectual disability.	1	2	3	4	5	6	7
3. I worry about not being able to control my worries and feelings about my child with intellectual disability.	1	2	3	4	5	6	7
4. My painful memories about my child with intellectual disability prevent me from having a fulfilling life.	1	2	3	4	5	6	7
5. Emotions relating to my child with intellectual disability cause problems in my life.	1	2	3	4	5	6	7
6. It seems like most people who have children with intellectual disability are handling their lives better than I am.	1	2	3	4	5	6	7
7. Worries get in the way of my success as a parent to my child with intellectual disability.	1	2	3	4	5	6	7
8. My thoughts and feelings about my child with intellectual disability get in the way of how I want to live my life.	1	2	3	4	5	6	7



Goal based outcome

- Carers were asked to set a goal after they've completed the values exercise.
- They were asked to rate how close they currently were to the goal (1-10).
- They were asked to rate it again at the follow up session 3 - 6 weeks after the second workshop.

Name _____ Date _____

My goal for the Parenting with Acceptance and Commitment group is:

.....

.....

Halfway to reaching
this goal

Goal not at all met 0 1 2 3 4 5 6 7 8 9 10 Goal reached



Qualitative feedback

- Semi-structured interview at the follow up session.
- 10 open-ended questions.
- Took place with the assistant psychologist who participated in the workshops.
- At home or the clinic 3-6 weeks after the workshop.

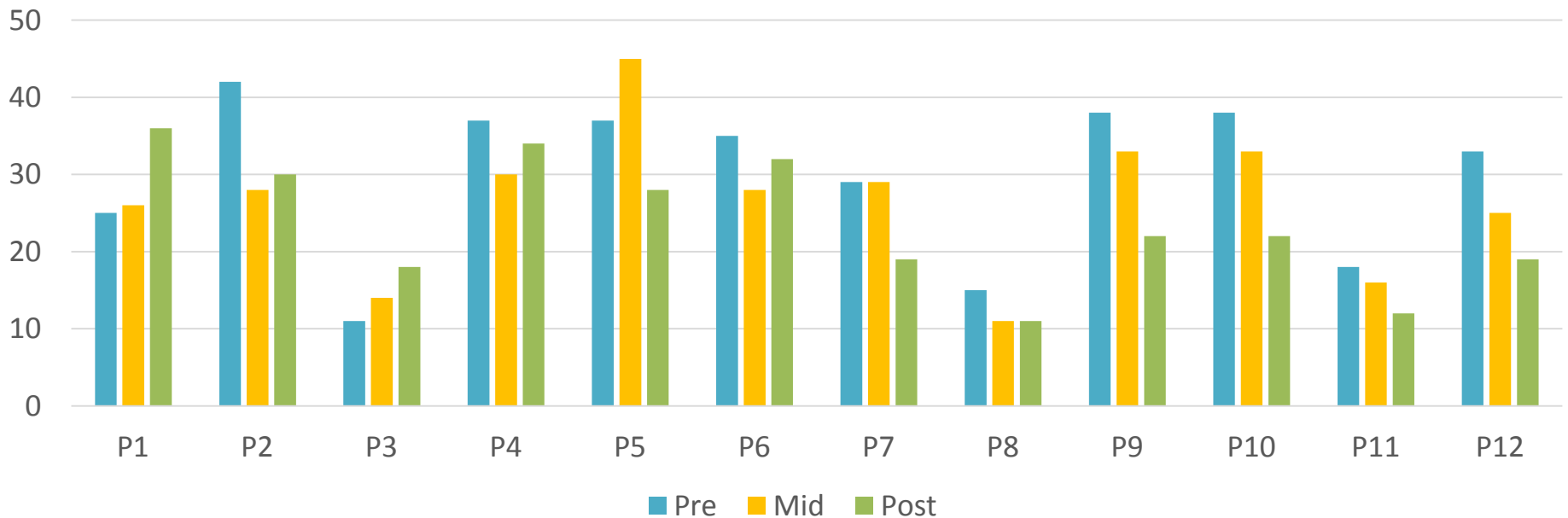


Results- Graph to depict levels of psychological acceptance



Central and
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Levels of Psychological Acceptance



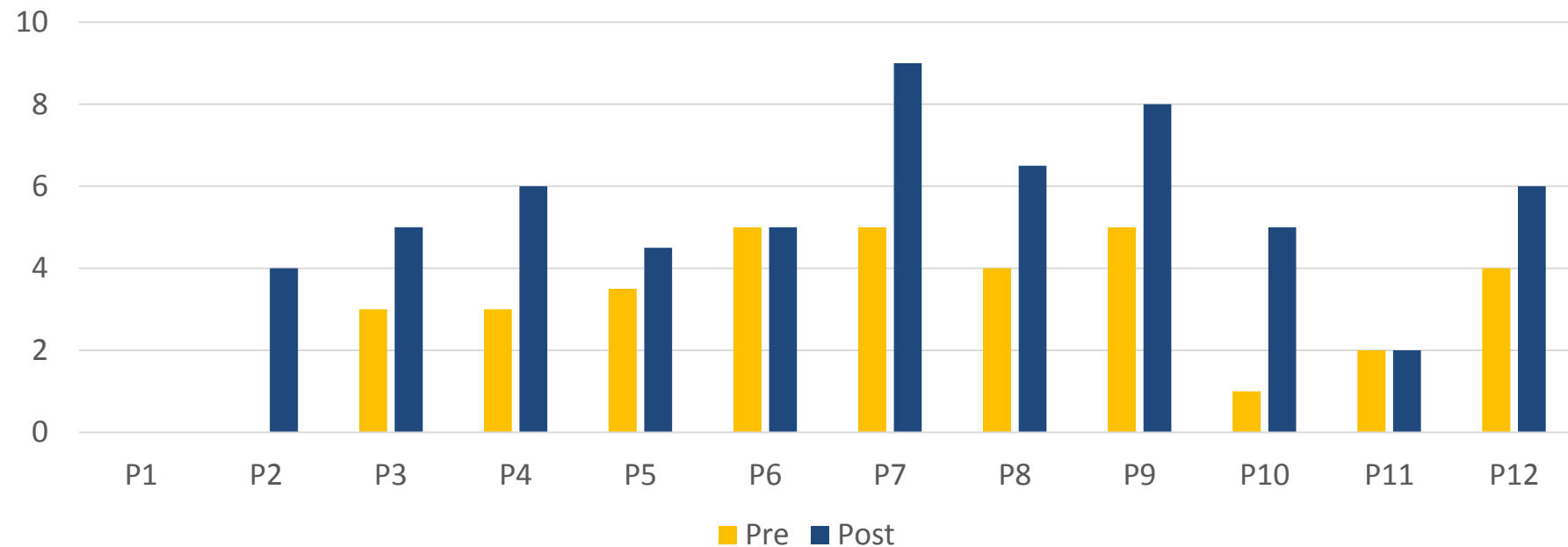


Results- Graph to depict goal rating



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Goal rating



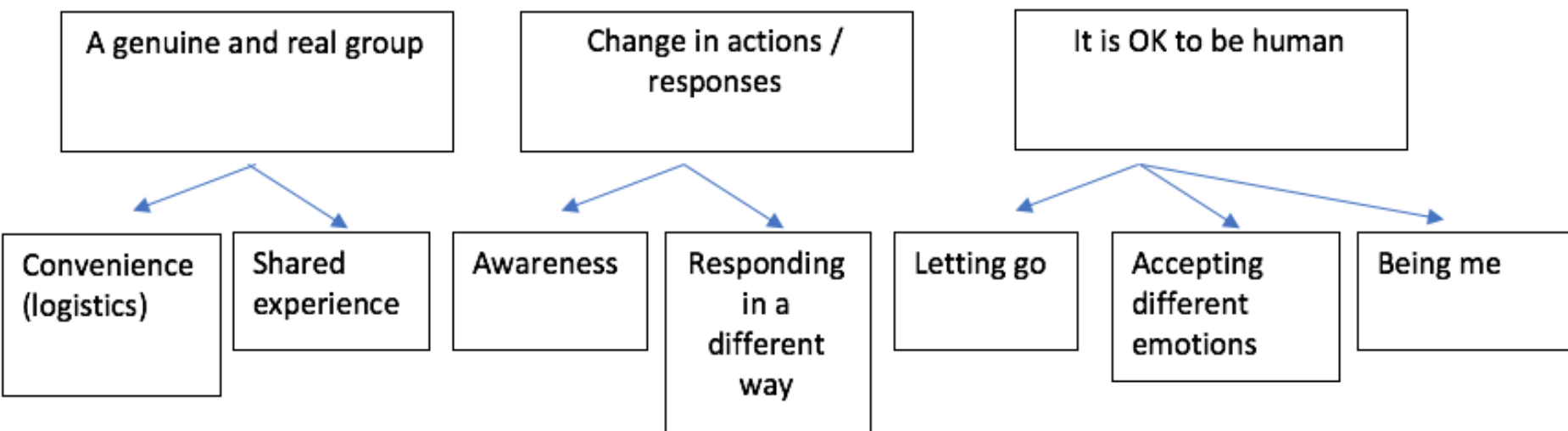


Qualitative Analysis

- Thematic analysis; a flexible approach that can also provide a rich account of data.
- Followed the process as described by Braun & Clarke (2006).
- We used open coding (didn't have preset codes).
- Conducted for 6 participants.



Thematic Map





Theme 1: A genuine and real group

Convenience

The place is fit for purpose. It is a blank canvas and it needs to be.

Timewise was perfect for me as my son was at school so it couldn't be better.

It was only down the road from us.

Timing was good, kids were in school and then the lunch was really good we didn't expect that you know, that was really sweet.



Theme 1: A genuine and real group

Shared Experience

It was so nice to know that there are other parents going through the same thing and were willing to share their experiences.

It was really empowering to know there is nothing wrong with how you are feeling and that you are not different{...} but to know in the group that everyone is in the same situation, and a lot of times you think your child is more challenging than mine, and why I can't cope.

How similar we were in thinking, well we're different but similar.





Theme 2: Change in actions

Awareness

I have noticed since I've done this I have looked at my environment and have been noticing things more when I walk down the street.

I am aware now that I'm tired and that I've had enough and I need to do something different.

Felt like we were on a rat race before and the workshop taught us to stop and look at where you're going. We didn't know where we were going.



Theme 2: Change in actions

Responding in a different way

Sometimes I will have to walk away from him, I'll make sure he's safe {...} I'm good at stopping now and taking a breath.

It is a process we're going to introduce to our kids as well {...} they can get worked up with each other. I would encourage them now to take a breath and reflect on what has upset them.

I have put less pressure on myself to do everything right all the time {...} now I have taken a step back and thought, what is the rush in doing this ?



Theme 3: It is OK to be human

Letting go

Because of the sessions it's like I've been bathed in sunlight, it feels like although I'm not actively doing the mindful exercise, it's like there in the back of my mind, it's like it's kind of become a part of me. I let things go more.

I used to think I need to be perfect and in control all the time. You can't be in control {...} if I want to cry I should just cry rather than holding it in, thinking I'm weak.



Theme 3: It is OK to be human

Accepting different emotions

I'm allowing myself to have moments not where I'm being weak, but where I'm allowing myself to not be as strong.

I actually felt human for once. It allowed me to openly share my more negative emotions and for someone to say to me it's ok to have those negative emotions.

I felt I needed to be happy and positive and handle everything. This gave me the go ahead to continue better myself but in a way that I'm also accepting all the negative aspects of my experience.



Theme 3: It is OK to be human

Being me

I have put less pressure on myself to do everything right all the time.

I felt relief. I realised I don't have to be perfect and great at everything and be the best mum. I just have to be me and if I can't handle something ... rather than holding it in, thinking I'm weak {...} these sessions allow you to think it's ok to be human.



Limitations & Challenges

- Relatively small sample.
- A more robust mixed-methods evaluation with a larger sample size and a waiting list control group is needed to confirm the outcomes.
- Difficult to encourage families to attend the workshops; how do we assess families' readiness?
- How do we engage the families who are less resilient and resourceful?
- How much did actually caregivers' behaviours (actions) change?
- Not able to do long term follow up (one year later)



Next Steps & Future Recommendations

- We will continue to run the ACT workshops for parents and carers who use our service (CAMHS) and evaluate the outcomes of this intervention.
- We will use ACT within individual sessions with parents and explore which of the 6 processes affect parents' behaviour and well being.
- ACT will become essential part of our Behaviour Support Plans as 'skills teaching for caregivers' (proactive intervention).
- We might form an ongoing support group for caregivers who use our service and monitor the outcomes.



Questions or Comments?



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