

DO YOU KNOW HOW I FEEL?

2nd Workshop, 26th January 2023



INTRODUCTION

Our journey so far has been exploring:

- Do you know how I feel?
- What is emotional wellbeing?
- How might emotions be expressed and responded to when people are communicating with us in ways other than words?

AIMS OF THIS WORKSHOP

- We are keen to ensure that our next steps are meaningful, useful and informed by people with severe and profound intellectual disabilities, their families and professionals in order to benefit their lives.
- From what we have found out so far do our interpretations make sense? Have we missed anything?

WHY MIGHT WE NEED AN EMOTION PROFILING TOOL / PROCESS?

- Because we care how people feel, feelings matter.
- To support emotional wellbeing.
- "Emotions allow us to be 'seen', to be 'known' by others, and in achieving that, they allow us to be persons."
Reddy, V. (2019) Meeting Infant Affect. Developmental Psychology, 55(9), 220-224.
- Having a tool that helps inform us how someone feels could help in all areas of relationships, care, support and education.
- Because other people don't always know what families know!

FINDINGS FROM OUR FIRST WORKSHOP

- People with profound intellectual disabilities express a wide range of emotions.
- People with profound intellectual disabilities may be high in emotional intelligence and their life experience should be acknowledged and respected.
- Families pick up on nuanced emotions.
- You have to be 'like a detective' to figure out what is going on.
- It takes a lot of time (6 months) to train others.
- You need to be careful about how much you are projecting (of your own emotions).
- How well you know a person is important. For example a person may 'talk with their eye movements'.
- Connection is key.
- Book knowledge is important but there needs to be common sense and sensitivity to connect.
- Some behaviours, instead of being valued as expressions, are labelled as challenging behaviours.
- If someone is quiet and withdrawn it is important to question why.

FINDINGS FROM OUR FIRST WORKSHOP

- WHAT MIGHT A TOOL LOOK LIKE

- Communication passports have been found not to improve outcomes (<https://kar.kent.ac.uk/91817/>).
- A tool should be for sharing interpretations.
- Amalgamated profiles are needed for school leavers.
- No jargon.
- Accessible to professionals, family and carers.
- The process is important, not just the product - a tool must support the process.
- Training is needed to support the use of a tool/process.
- Needs to be fluid, not static.

“

© NAC 2023

Language shows us that
naming an experience
doesn't give the experience
more power, it gives us the
power of understanding
and meaning.

Brené Brown

ATLAS OF THE HEART



However, it has been found that we may not be very good at identifying emotions, even in ourselves. Over the course of 5 years, Brené Brown collected surveys of more than 7000 people who were asked to list and name all the emotions they could recognise and name, as they were experiencing them. The average number of emotions named was 3 - happy, sad, angry.

Brown, B. (2021) Atlas of the Heart: Mapping Meaningful Connection and the Language of Human Experience. Vermilion: London.

How do we observe and interpret how someone else feels? Especially when they cannot tell us with words.

How do we encompass cultural and developmental factors?

EMOTIONS AND THE BODY

Emotions are embodied - they have a physiological nature, multimodal and dynamic.
(Keltner et al, 2019)

Emotions are relational - affected by the feelings of others.

Emotions emerge through communication and help
'punctuate the dynamic flow of communication by opening (or closing) opportunities for individuals to experience themselves in relation to others' (Garvey and Fogel, 2008, p.63).

Observation of bodily signs, attunement, empathy and awareness of our own feelings and emotions in relation to another person may be key for identifying emotions in others. Especially those who cannot express with words and who are reliant on us to meet daily needs.

Could the embodied and relational nature of emotions be keys to answering 'Do you know how I feel?'

EMOTIONAL CONSCIOUSNESS: NEUROSCIENTIFIC EVIDENCE

Consciousness is the state of being aware and responsive. It is not the same as “intelligence”.

Children without a cortex (the “thinking” part of the brain) show emotional awareness/consciousness.

Emotions are critical in stimulating learning by experience.

Empathy with others seems to develop through mirroring emotional behaviours.

Memories are carried in the body, and are emotionally saturated.

Mark Solms (2020) The Hidden Spring, Profile Books; Hatrield et. Al., 2014; Vaisever, 2020

CULTURAL DIFFERENCES IN EMOTION

High Arousal cultures: Western, individualist

Emphasis & attention on energetic, dramatic emotions: eg. astonishment, excitement, delight, joy, distress, frustration, fear, anger, annoyance

Low Arousal cultures: East Asia, collectivist

Emphasis & attention on calmness, content, pleased, relaxed, satisfied..boredom, depression, sadness, gloom, tense

Different cultures report experiencing emotions differently - And define terms differently

Happiness... Western cultures define as upbeat, Chinese as solemn, quiet and reserved (Lim, 2016)

EMOTIONAL DEVELOPMENT

There is still a lot to learn about how we begin to express emotions

- There are recognised stages of emotional development
- By 3-4 months infants seem to distinguish pleasant/unpleasant
- By 12 months, infants can recognise differences between happy, sad, angry in images - but this may simply be consistent response to positive or negative.
- They need vocal cues as well as facial expressions
- Infants learn about emotions when caregivers respond to their behaviours, name them and pair them with expressive behaviours

Hoemann, K. Xu, F. & Barrett, L. (2019). D, Emotion words, emotion concepts, and emotional development in children: A constructionist hypothesis. Developmental Psychology, 55 (9), 1830–1849

DO YOU AGREE?

Severe or profound intellectual impairment does not determine the capacity to experience the same range of emotions and feelings as other human beings.



Emotional Wellbeing

What is it?

How do we get it?

How do we know if we have it?

[illegible]

THEMATIC ANALYSIS FINDINGS

Emotional wellbeing is associated with the following needs and feelings:

NEEDS

- Connection and belonging
- Self-awareness
- Expression (authentic)
- Autonomy
- Resilience and regulation

FEELINGS

- Safety
- Self-value
- Good feelings
- Ease and balance
- Accomplishment

EMOTIONAL WELLBEING NEEDS



Connection and belonging

Sensing connection and belonging with others, oneself and the environment

Self-awareness

Being able to sense our own feelings, knowing who we are

Expression (authentic)

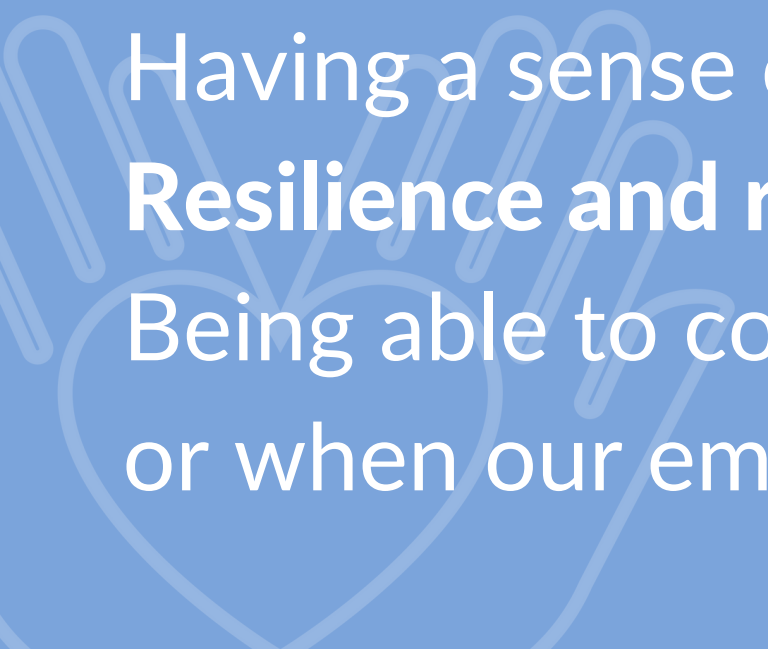
Being able to express our true feelings, pleasant and unpleasant, not having to hide feelings and emotions

Autonomy

Having a sense of personal control, agency, self-direction (closely related to hope)

Resilience and regulation

Being able to cope and keep safe and well when things do not go how we want them to or when our emotions are difficult



EMOTIONAL WELLBEING FEELINGS

Safety

Not just being safe, but when it is safe, also feeling safe in ourselves, the world, our environment and with others

Self-value

Having a feeling of worth, that we are and that we mean something

Good feelings

Experiencing pleasurable emotions and feelings such as joy, excitement, interest, awe

Ease and balance

Being able to experience calm, not feeling overwhelmed by feelings or out of control

Accomplishment

Feeling a sense of achievement and contribution

What do you think is important for the emotional wellbeing of people with severe or profound intellectual disabilities?



Good support. People that know them well. Opportunities to feel valued. Connecting with others and their community. Time to relax. Sense of control. Being listened to. Opportunities for fun and joy. Allowed to express when unhappy. (Sibling)

A caregiver that is in tune with the person. Knowing their small queues and nuances. Supporting opportunities to develop regulation (professional)

TrustCareKindnessOpen-mindedNon-judgementalAwarenessCompassion UnderstandingPatience(Professional)

For people with PMLD, quality of life is everything, I feel. They should feel valued and able to contribute in their life. They should be celebrated as individuals, access to choices, and some level of risk. They must have control in their lives.

Carers understanding and implementing what is important to the person, focussing on their quality of life, and being able to recognise signs of good and poor emotional wellbeing (Professional)

That they are not ignored or marginalised; that they are included; that they have experiences; that they are listened to and their communication and their meaning is heard, understand responded to.

Detailed documentation about their communication to include emotions

They have people who truly care & put effort into knowing them as an individual - into 'hearing' them with all of their senses - communicating with them in the way they need in that moment. Ensuring all basic

To be 'listened to', empathy, well trained staff, receptive carers, open-mindedness, comfort, needs met, positive relationships, laughter, control where possible, different environments depending on needs



WHAT WOULD A TOOL LOOK LIKE?

Digital?

Paper?

Words, pictures, video?

Online/ offline?

Process / product



WHO WOULD THE TOOL BE USED BY:

- 1) Families
- 2) Professionals
- 3) Anyone?



CHALLENGES

- 1) Getting the extraordinary depth of knowledge and understanding out of relatives' brains and into a tool.
- 2) For the tool/process to be simple enough to be usable, but as complex as necessary to be useful.

BREAKOUT ROOMS

What would a 'Do you know how I feel' tool need to include?

Please think about process, product and any training and resources that might be needed.

EXISTING TOOLS AND RESOURCES

- Affective Communication Assessment
<http://drmarkbarber.co.uk/ACAOWNERSMANUAL.pdf>
- Insension Questionnaire and Resource <https://www.insension.eu>
- Mysigns.health <https://www.mysigns.health/>
- Disability Distress Assessment Tool
https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf
- Emoji feelings profile available from info@storysharing.org.uk
- Needs and Feelings Inventories
<https://www.cnvc.org/training/resource/feelings-inventory>