

# Sensory activity and people with profound and multiple learning disabilities

October 2021

RCOTSSPLD PMLD Network Study Day

**David Haines**

**Principal Lecturer, University of Brighton**

[d.Haines@brighton.ac.uk](mailto:d.Haines@brighton.ac.uk)

Royal College of  
Occupational  
Therapists



Specialist Section  
People with  
Learning Disabilities



**University of Brighton**

# Plan for this session

- + Present some key findings from the 2018 RCOT SSPLD survey of Specialist Section members re their use of Sensory Activity
- + Discuss whether:
  - + there is a need for development of resources or a way of sharing resources in this area
  - + Who might take this forward and how
  - + How this might be supported by the PMLD Network/ the NEC of RCOTSSPLD



# What do we mean by “sensory activity”?

“[Meaningful activities for people with profound and multiple learning disabilities] recognise that many people ... experience the world largely on a sensory level and take this into account”

Mencap 2011, p.40

For people with profound and multiple learning disabilities, meaningful or authentic engagement in occupation implies:

- + engaging in activity in non-typical ways
- + engaging in developmentally-appropriate “*sensory activity*”, or “*doing regular things in a very sensory way*”.
- + understanding the sensory level at which someone might be functioning and how this impacts on the level of engagement in activity they are likely to be able to achieve and what they are likely to find meaningful.

Meaning to these individuals lies in the sensory aspects of activities, paying maximal attention to process rather than end result

Haines 2015



**University of Brighton**

# Survey of RCOT SSPLD members



[www.rcot.co.uk/](http://www.rcot.co.uk/)  
specialistsections

Royal College of  
Occupational  
Therapists



improving health  
through  
occupational therapy

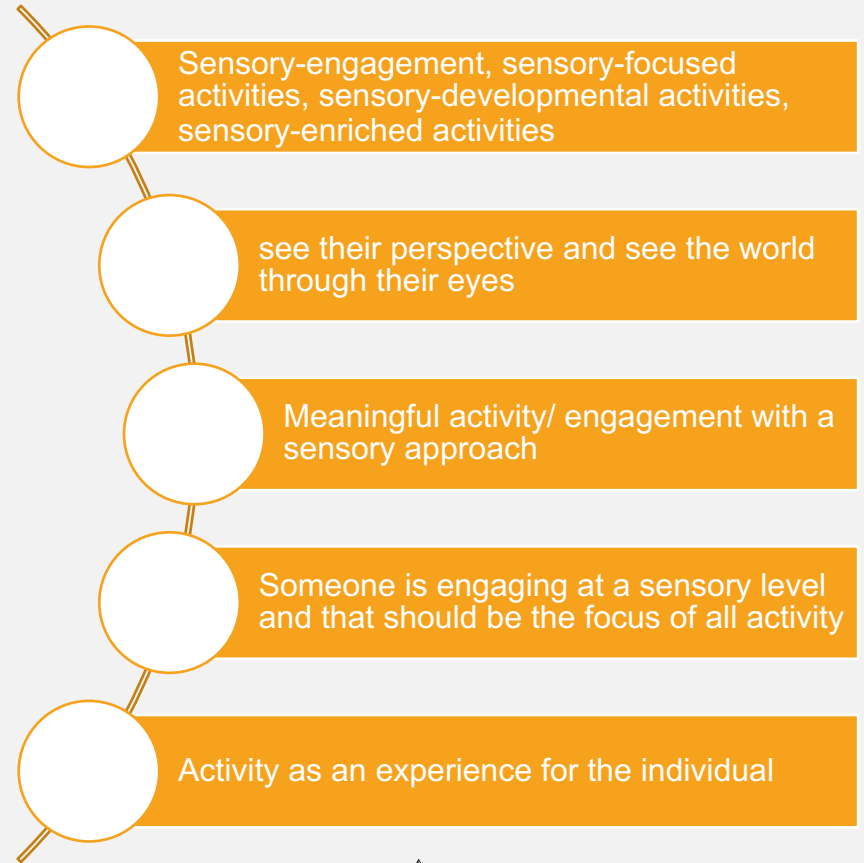
- + Service evaluation survey
- + Online using [onlinesurveys.ac.uk](http://onlinesurveys.ac.uk) (BOS)
- + Summer 2018
- + 19 respondents
- + Mean years working as an OT = 19.65  
(range 1-37, SD 9.98)
- + Mean years working in LD = 15.29  
(range 1-30 years, SD8.69)
- + Detailed responses – approx. 15,000 words
- + Qualitative data analysed using thematic analysis



**University of Brighton**

**Respondents generally agreed with the definition of sensory activity**

**Additional/ alternative wording was suggested by some**



# Key themes

- + People's typical levels of engagement and support workers' understandings
- + Occupational therapy and sensory activity
- + General principles
- + Indicators of engagement
- + Getting to know people well enough
- + Building close, creative and responsive relationships
- + The kinds of activities that work
- + Theory that supports sensory activity
- + Resources used/ created



# Typical levels of engagement

&

# Support workers' understandings of sensory activity

+ Levels of engagement vary hugely/ mixed understandings

Some excellent, enthusiastic, open-minded support workers

Pitching it at wrong developmental level, one size fits all

Misunderstanding independence

Engagement opportunities missed

Values base

Structural issues

Therefore important for us to get involved



**University of Brighton**

# Occupational therapy use of sensory activity

We do a lot of  
this sort of work

Good outcomes:  
now a natural  
part of their  
thinking

Can be seen as  
a lower priority –  
focus on those  
at obvious risk



**University of Brighton**



Individualise, offer  
new opportunities

It is complex – be  
flexible

Pitch at the right  
level

Don't assume you  
will always get it  
right

Persistence – it  
takes time, offer  
more than once

A small period of  
engagement =  
success

## General principles underpinning sensory activity 1

Plan beforehand so  
everything is to  
hand, best time of  
day

Regular  
opportunities –  
positive value in  
smallest opportunity

Environments that  
maximise  
opportunity

Cover all senses,  
but one type of  
activity at a time

Encourage choice  
and control

Share positive  
examples e.g.  
photos/videos of  
them engaged

Careful  
observations –  
before, during and  
after

Involve others –  
SALT, students

Get to know them  
well – level of  
engagement and  
sensory  
preferences

## General principles underpinning sensory activity 2



**University of Brighton**

What might indicate  
that someone is  
engaged?

Knowing the  
person well

Vocalisations

Variation in  
mood

Choosing or  
doing something

Persisting,  
trying again

Movements

Not necessarily  
physically doing  
something



**University of Brighton**

# Getting to know people well enough to interpret subtle behaviours meaningfully

Spending time with them

Observing them

Speaking to people who know them well

Sensory preference assessment

Intensive interaction

Time consuming



# Do you use standardised assessments ...?

- + No (but might do) 5
- + Pool Activity Levels 9
- + Sensory Profile, Sensory Integration Inventory (revised) 5

Others (1 or 2)

- + Paediatric Pain Profile
- + MOHO Explor
- + AMPS
- + Disability Distress Assessment Tool



**University of Brighton**

# Building close, creative and responsive relationships

Authentic engagement in occupation for people with PMLD comes out of a close, creative and responsive relationship between the individual and the person supporting engagement ... the supporter needing to remain '*in step*'.

Haines 2015

Really being with them

Adapting communication

The relationship builds through finding ways to engage them

Mirroring

Humour

Imagination



**University of Brighton**

**What kind of activities  
work?**

**Respondents had  
LOADS of ideas!**

Personal care  
activities

Household  
activities

Sensory  
room  
activities

Targeting  
specific  
senses

Multi-sensory  
stories, book  
in a bag

Outside the  
home



**University of Brighton**

# What theory can support use of sensory activity?

## 1. Theories chosen from list

\*Coupe O’Kane and Goldbart (1998)

^Mansell & Beadle-Brown 2012

\*\*Coia and Handley 2008, Nind 2009

Occupational science 6

Pool activity levels 16

Levels of intentional/ pre-intentional communication\* 4

Sensory integration 13

Person-centred active support^ 12

Intensive interaction\*\* 15





# What theory can support use of sensory activity?

## 2. Other theories mentioned (free text)

Vona du Toit  
Model of  
Creative Ability

Partial  
participation

Volition

Developmental  
theories e.g.  
Piaget

Person-centred  
planning

MOHO, AMPS



What theory can support use of sensory activity?

3. Theories from given list that respondents did not mention

Co-occupation

(Pierce 2003; Pickens and Pizur-Barnekow 2009)

Affect

attunement

(Griffiths and Smith 2015)



**University of Brighton**

# How do you use theory?

Avoid jargon,  
use own words

I explain the  
basic theory

Clearly link to an  
individual

Explain in report,  
guidelines,  
plans, recording  
sheets

Demonstrate  
more than  
explain

Training  
package,  
materials

I don't give them  
the theory – they  
switch off



**University of Brighton**

# Resources used and created to support and inform sensory activity

Sharing published resources

Suggestions for how to do sensory activity on a budget

Training packages

Always have a box of 'stuff' in the cupboard

General guidance, e.g. re sensory room

Individualised OT report etc



# Individualised occupational therapy report and resources

Report template

Activity guides,  
activity cards

Info re sensory  
engagement, using  
everyday items in a  
sensory way

Laminated  
schedules and  
prompts

Engagement and  
activity passports

Engagement  
questionnaires

Sensory response  
monitoring sheet

Sensory diet plans



**University of Brighton**

# Conclusions

- + Some occupational therapists are using sensory activity a lot with people with learning disabilities and those that support them
- + Although overlapping, the findings do suggest that sensory activity is a distinctive intervention from sensory integration
- + We are passionate about this kind of work and its potential for improving people's occupational lives!
- + There are untapped resources related to sensory activity in our teams which could be shared
- + Surveys can produce surprisingly excellent qualitative data if you ask the right questions of the right people



# Taking it forward

- + Where do we take the findings from this service evaluation survey, undertaken on your behalf, next?
- + What resources might be useful for the PMLD Network/ RCOT SSPLD to consider developing?
- + Might you be interested in becoming involved in the next stage?

Royal College of  
Occupational  
Therapists



Specialist Section  
People with  
Learning Disabilities



**University of Brighton**

# Any questions?

For further information contact:

David Haines

[d.haines@brighton.ac.uk](mailto:d.haines@brighton.ac.uk)

01273 643661

Royal College of  
Occupational  
Therapists



Specialist Section  
People with  
Learning Disabilities



**University of Brighton**



# References

Coia P, Handley AJ (2008) Developing relationships with people with profound learning disabilities through intensive interactions. In: Zeedyk MS, ed. *Promoting social interaction for individuals with communicative impairments: Making contact*. London, England: Jessica Kingsley Publishers. 102-118.

Coupe O'Kane J, Goldbart J (1988) Communication before speech : normal development and impaired communication. Melbourne: Law Book Co.

Griffiths C, Smith M (2015) Attuning: A communication process between people with severe and profound intellectual disability and their interaction partners. *Journal of Applied Research in Intellectual Disabilities*. Early view online 5.3.15

Haines D ( 2015) Occupational therapy supporting people with profound intellectual disabilities to engage in occupation at home. PhD Thesis, University of Brighton.

Mahoney W, Roberts E (2009) Co-occupation in a day program for adults with developmental disabilities. *Journal of Occupational Science*, 16(3), 170-179.



**University of Brighton**

# References

Mansell J, Beadle-Brown J (2012) *Active support: enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley.

Mencap (2011) *Lambeth PMLD Project: understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth*. London: Mencap

Nind M (2009) Promoting the emotional well-being of people with profound and multiple intellectual disabilities: A holistic approach through intensive interaction. In: Pawlyn J, Carnaby, S, eds. *Profound intellectual and multiple disabilities: Nursing complex needs*. London: Wiley-Blackwell. 62-77.

Pierce DE (2003) *Occupation by design: building therapeutic power*. Philadelphia PA: F A Davis.

Pizur-Barnekow K, Knutson J (2009) A comparison of the personality dimensions and behavior changes that occur during solitary and co-occupation. *Journal of Occupational Science: Australia*, 16(3), 157.

Pool J (2012) *The Pool Activity Level (PAL) instrument for occupational profiling: a practical resource for carers of people with cognitive impairment*. 4th ed. London: Jessica Kingsley

