

BRINGING MINDS TOGETHER EXPLORING COGNITIVE STIMULATION THERAPY (CST) FOR ADULTS WITH INTELLECTUAL DISABILITIES

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Avista

Trinity Centre
for Ageing and
Intellectual Disability



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

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Aonad Pleanála & Forbartha Altranais
& Cnáimhseachais, Átha Cliath & Thoir Theas

Nursing & Midwifery Planning &
Development Unit, Dublin & South East

Avista



BACKGROUND



Higher risk of developing dementia
(McCarron et al., 2017).



Cognitive stimulation therapy evidence
based (Woods et al., 2006; Saragih et al.,
2022).



Recommended by NICE and HSE (NICE, 2018;
Begley et al., 2023).



Gap in literature for intellectual disability.

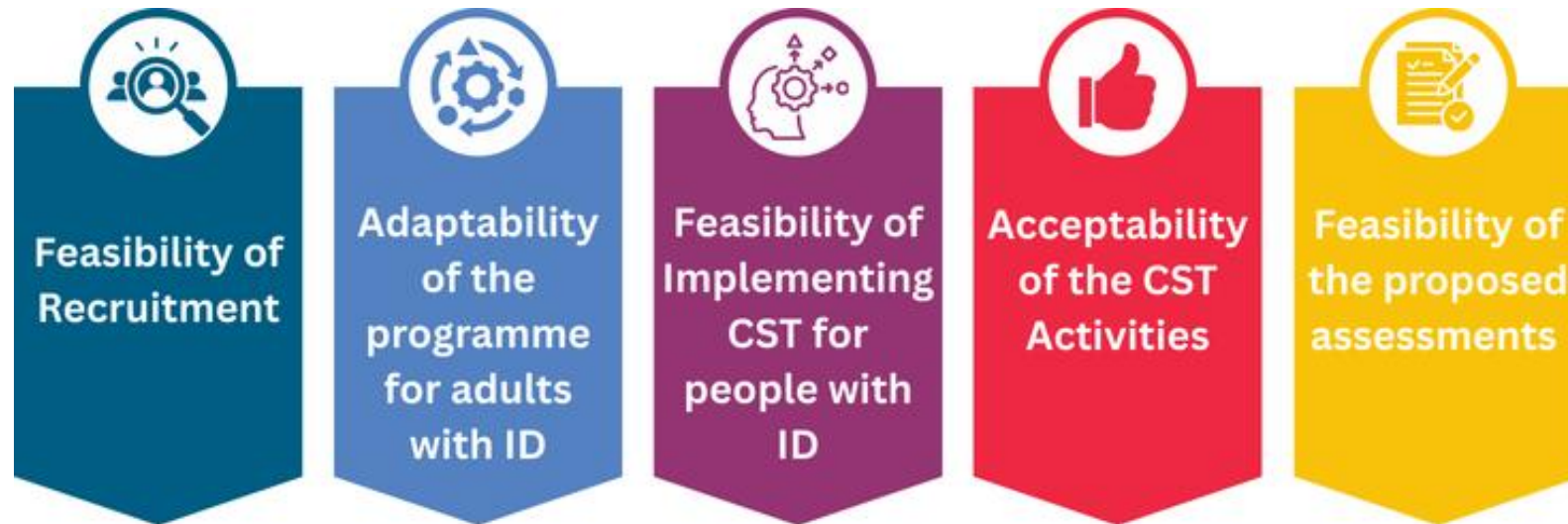




PROJECT AIM AND OBJECTIVES

The aim of the project was to **investigate the feasibility** of implementing **group Cognitive Stimulation Therapy (CST)** with adults who have an **intellectual disability** and are **at risk** of developing **dementia**.

The Primary Objectives were to explore



THE SECONDARY OBJECTIVES WERE



Assess the impact of CST on

- ✓ **Quality of Life**
- ✓ **Global function**
- ✓ **Cognition**



Outcomes measured at **baseline** and **post intervention** using standardised tools.



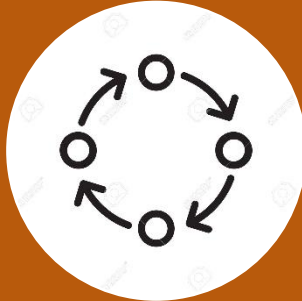
METHODOLOGY



Ethical approval was granted for this project by the Faculty of Health Sciences, Trinity College Dublin and Avista Research Ethics Committee.



Informed consent was obtained from participants facilitated using **easy-to-read** material and **total communication** approach



Validation by the **TCAID PPI** panel with **lived experience** of intellectual disability integrated into every element of project.



The study used a **mixed-methods** convergent design integrating both **quantitative and qualitative** approaches



Data from primary objectives **analysed** using **descriptive statistics**.



METHODOLOGY



- Public and Patient Involvement (PPI) with individuals with lived experience.
- Consultation and Collaboration



METHODOLOGY

Inclusion Criteria

- ✓ Adults with **mild to moderate** level of intellectual disability.
- ✓ **Ability** to provide **explicit consent**.
- ✓ **Age criteria** for individuals with **Down syndrome** : **35 years** and above.
- ✓ **Age criteria** for individuals with intellectual disability from **other aetiology**: **50 years** and above.

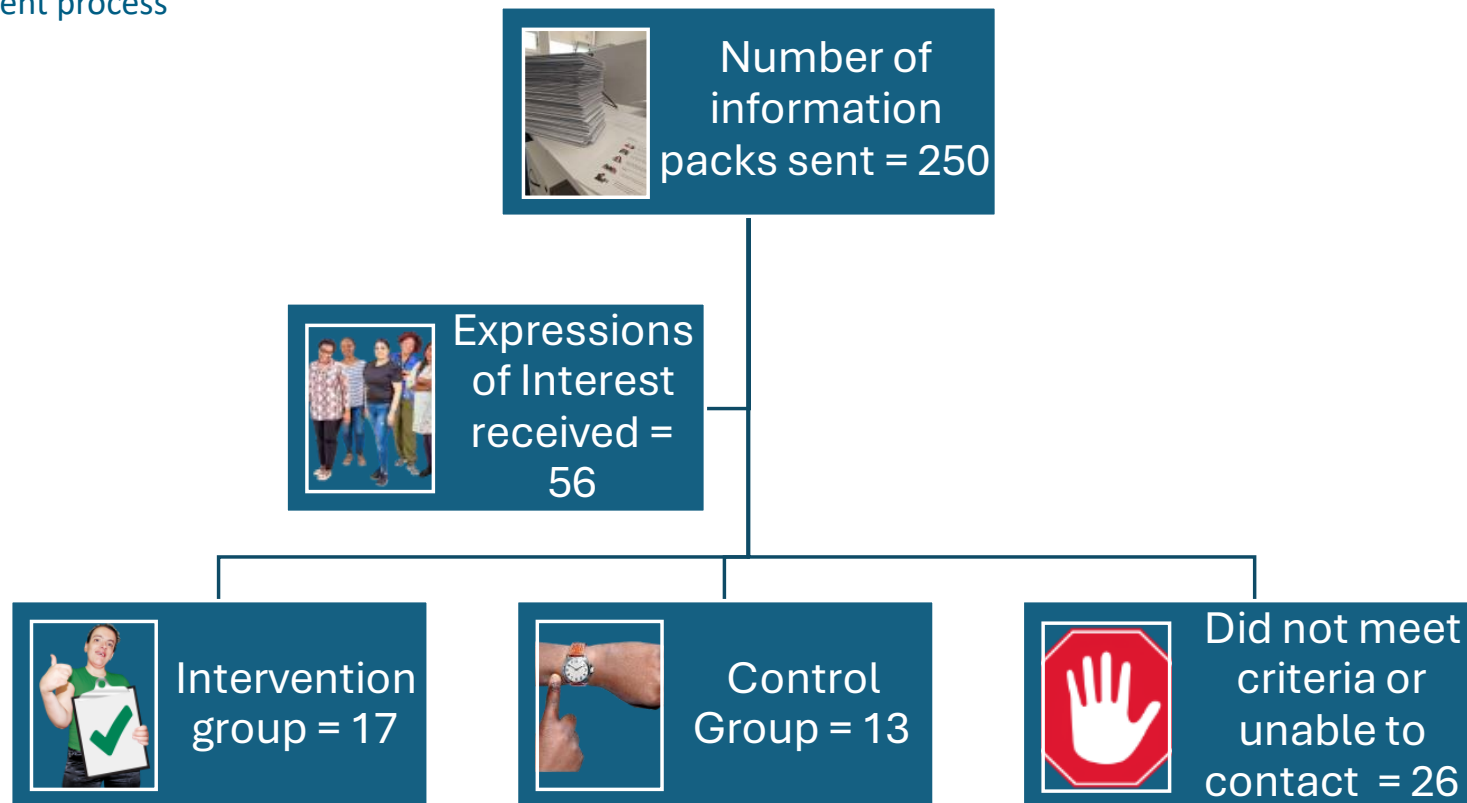
Exclusion Criteria

- ✓ Diagnosis of dementia.
- ✓ Adults **under** the age of **35 years**.
- ✓ Adults with **severe to profound** levels of intellectual disability.



METHODOLOGY

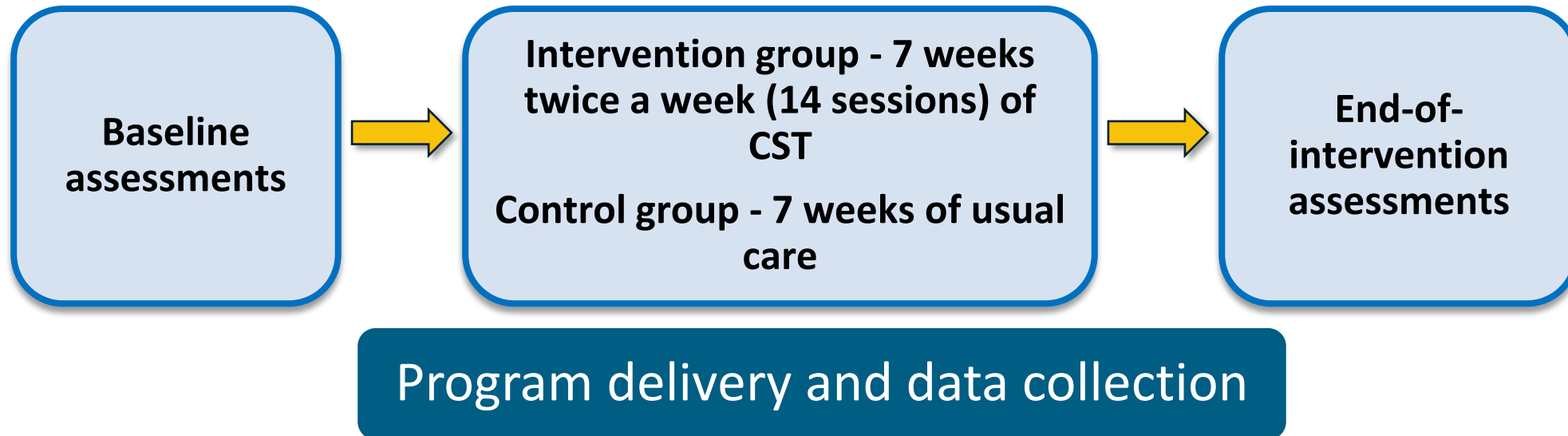
Figure: Recruitment process



Cluster randomisation with three clusters assigned to an intervention and control group based on geographical location.



METHODOLOGY



- CST program was delivered by Avista CST facilitators.
- Supplementary CST Manual adapted for adults with an intellectual disability (Ali et al., 2023).
- Calibration session completed to ensure **Fidelity** in programme delivery.
- Data was collected for the intervention group after each session using '**group facilitator observation log**' and '**participant feedback form**'.
- Assessments.

Response rate at baseline and post intervention was 96.6%



DEMOGRAPHICS



**Age mean
(s.d.)**

51.6

**Age (Down
Syndrome)
mean (s.d.)**

44.6

**Age
(Intellectual
Disability other
aetiology)
mean (s.d.)**

56.8

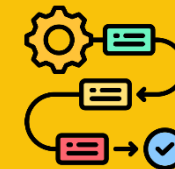
**Female: male
24: 6**



FINDINGS



RECRUITMENT AND RETENTION



**Recruitment
rate
53.5%**

**Retention
rate
100%**

**Dropout
rate
0%**



FEASIBILITY OF IMPLEMENTATION OF CST



On an average,
participants attended
11 out of 14 sessions.

17.6% participants
attended all **14**
sessions.

**Two Group
Facilitators.**

**Designated
Space.**

✓ ACCEPTABILITY



Enjoyment

12 sessions

Easy

6 sessions

Repeat

12 sessions

Activity completion

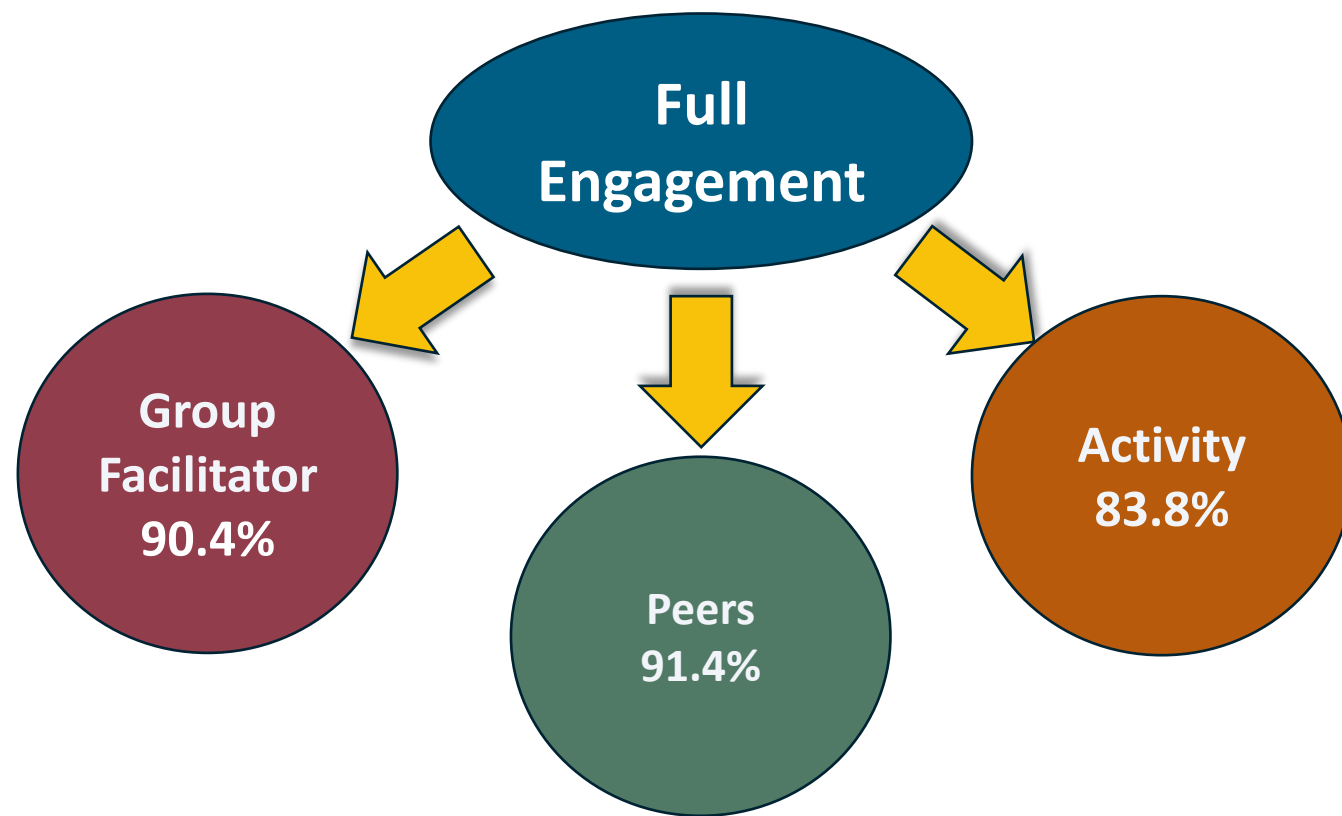
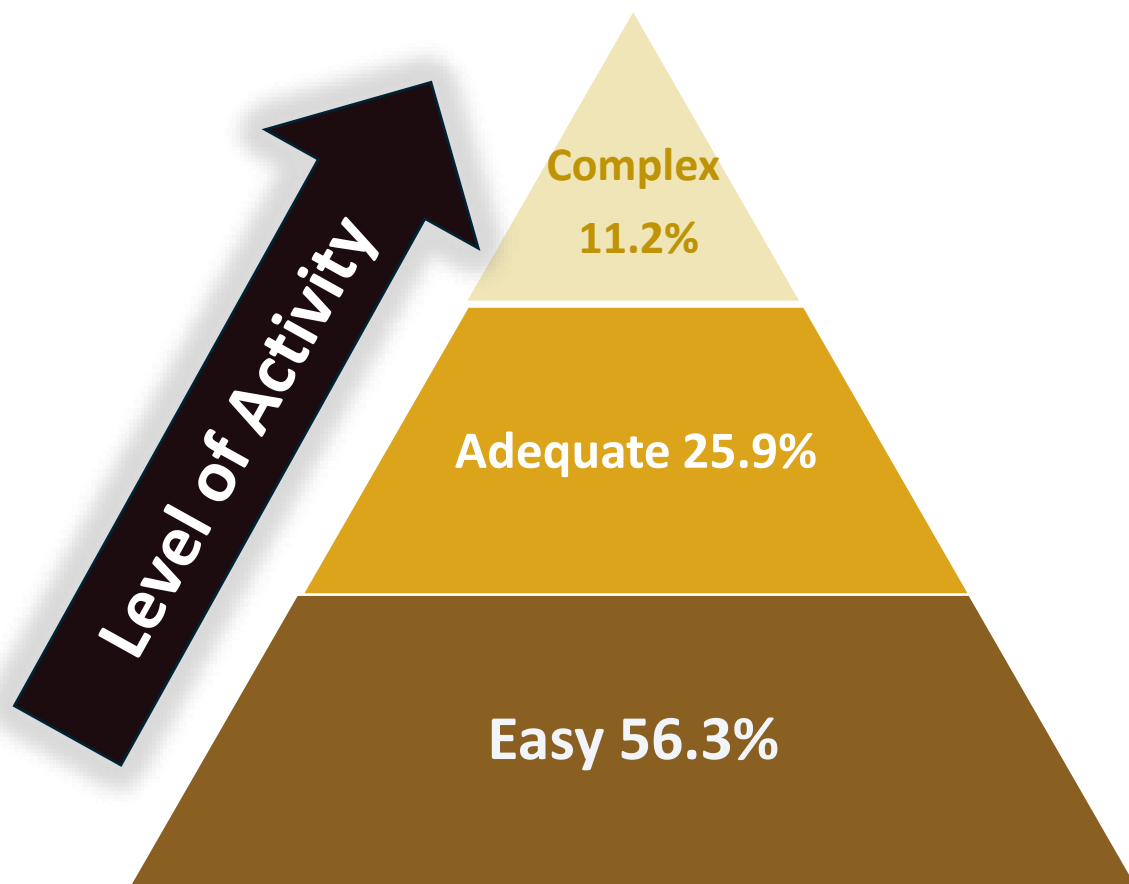
Independently
74.1%

With support
24.4%





APPROPRIATENESS





PARTICIPANTS' VOICES



"It's very good, it gave me confidence"



"Would tell others to go to the group"

"Have a laugh, have fun, talk to your friends"

"Make me happy"





FACILITATORS' FEEDBACK

- ✓ Ease of Implementation.
- ✓ Adaptability.
- ✓ Social interaction/engagement.
- ✓ Cognitive benefits.
- ✓ Complements other activities in day services.
- ✓ Promotes consistency and activity sampling in each session.

fun and entertaining
stimulating
engaging
involved
inclusion
fun
group building

developing relationships
friendship
connection proud
belonging
banter confidence
feeling of success
the joy in the sessions



OVERARCHING THEMES



Themes generated from
reflexive thematic
analysis (Braun and Clarke, 2006).

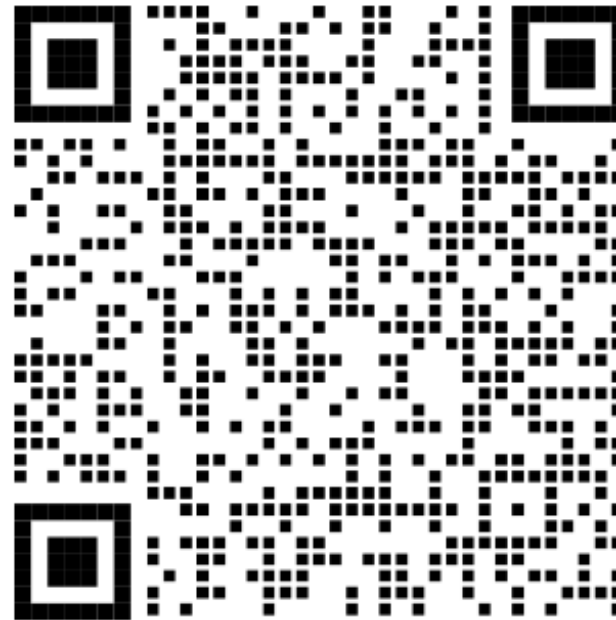




REPORT LAUNCH



<https://avista.ie/stories/avista-and-trinity-college-dublin-launch-cognitive-stimulation-therapy-study/>



MY CST EXPERIENCE



Avista



**I am a
huge
Manchester
City fan**

**My name
is
Stephen**



**I enjoy
music,
sport &
dancing**

**I have an
active role in
Down
Syndrome
Ireland, and I
help with
Avista events**



Avista



WHAT IS CST FOR ME?



It is a fun way to
keep your brain
working well.



It is games to
help with
thinking.



It can help you
feel better and
stay on your
toes.



WHY DID I WANT TO TAKE PART?

**I like trying
something new.**

I like a challenge!

**I like meeting up
with friends.**



SESSIONS I ENJOYED

With our eyes closed or using blindfolds, we



Smelled



Tasted



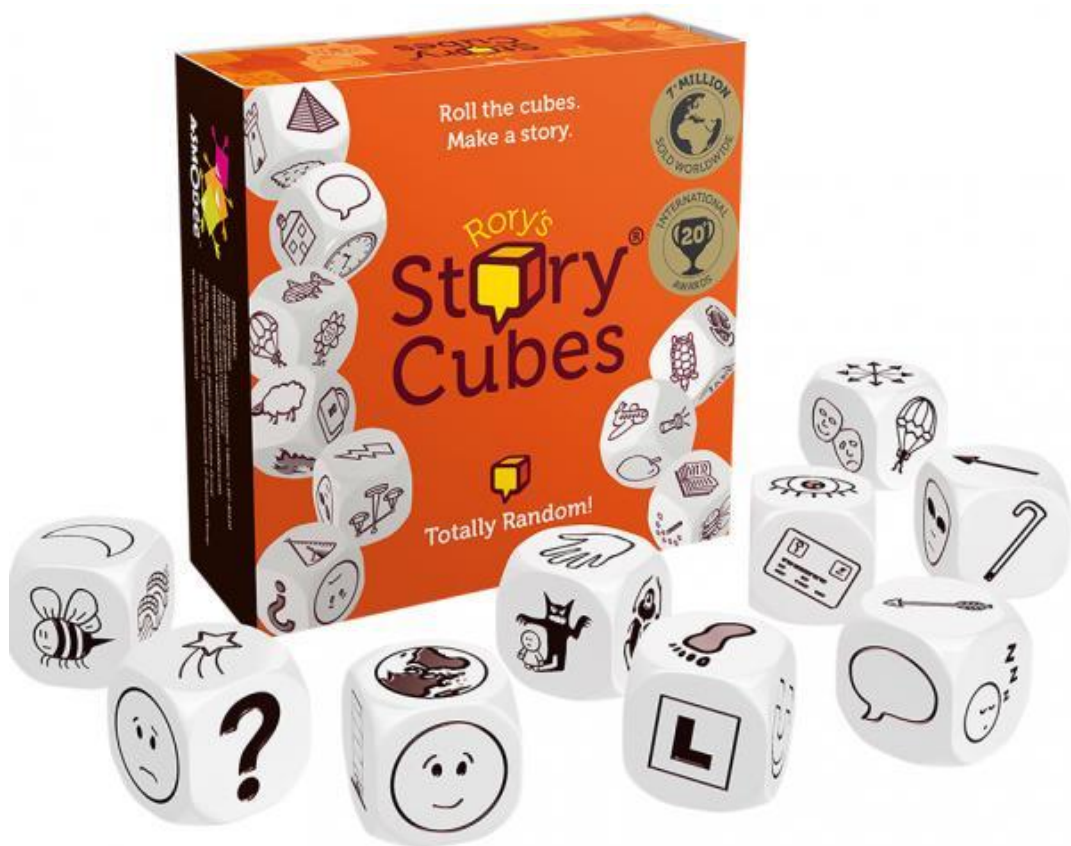
Touched foods

To guess what they were!





SESSIONS I ENJOYED



Using story cubes I used my imagination and made up this story

When I was fast asleep, I got stung on my hand by a bee.

When I woke up, I wished it was a dream!



SESSIONS I ENJOYED



**We looked at
pictures and tried to
guess who or where
they were.**



WHAT I FOUND DIFFICULT

At first, I did not know what to expect.

But after the first session, I was comfortable.

Nothing in the session was difficult....

...but I had to think hard for most sessions.

WHAT I LEARNED ABOUT MYSELF



**I like
being part
of a
group.**



**I like
meeting
people.**



**I like using
my brain
and trying
new things.**



**It felt good
when my
input
helped.**



WHAT IS GOOD ABOUT CST



It is a chance to meet new people.

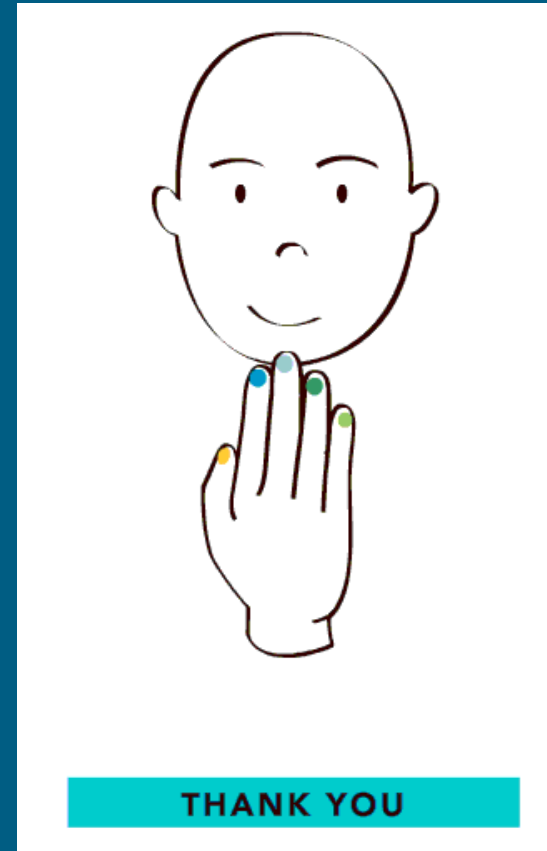


It keeps your mind active.



It is a lot of fun!

THANK YOU FOR LISTENING





Acknowledgements

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Expert international advisory panel

TCAID PPI panel members

Dr Afia Ali and Professor Angela Hassiots, University College London

Vincent O' Neill, Clockwork productions





REFERENCES



- Ali, A., Aguirre, E., Carter, J., Hoare, S., Brackley, K., Goulden, N., Hoare, Z., Clarke, C. S., Charlesworth, G., Acton, D., & Spector, A. (2023). Group cognitive stimulation therapy versus usual care for people with intellectual disabilities and dementia (CST-IDD) in the UK: protocol for a mixed-methods feasibility randomised controlled trial. *BMJ Open*, 13(4), e072391. <https://doi.org/10.1136/bmjopen-2023-072391>
- Begley, E., Gibb, M., Kelly, G., Keogh, F., & Timmons, S. (2023). Model of care for dementia in Ireland. National Dementia Services.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Health Service Executive (2020) Estimated Dementia Prevalence. Available from: <http://dementiaphathways.ie/permacache/fdd/cf3/792/e223695cf65ee173882bdc394de3a8fc.pdf>
- McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research*, 61(9), 843-852. <https://doi.org/10.1111/jir.12390>
- National Institute for Health and Care Excellence. (2018). Care and support of people growing older with learning disabilities (NG96). Retrieved from: <https://www.nice.org.uk/guidance/ng96>.
- Saragih, I. D., Tonapa, S. I., Saragih, I. S., & Lee, B. O. (2022). Effects of cognitive stimulation therapy for people with dementia: A systematic review and meta-analysis of randomized controlled studies. *International journal of nursing studies*, 128, 104181. <https://doi.org/10.1016/j.ijnurstu.2022.104181>
- Woods, B., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation therapy in dementia. *Aging & mental health*, 10(3), 219–226. <https://doi.org/10.1080/13607860500431652>



Avista

Memory Clinic

CST, nurturing curiosity, confidence,
& connection