## Title

Proactive cognitive stimulation for younger adults with Down syndrome.

A feasibility randomised control trial.

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PMID: 40926761 ; DOI: 10.1111/jar.70120

## Abstract

**Background.** Most adults with Down syndrome develop Alzheimer's disease (AD) pathology in their 30s, yet research into cognitive health programmes for this group remains limited. **Method.** A mixed-methods feasibility randomised control trial (RCT) evaluated an adapted, manualised group-based cognitive stimulation therapy (CST) programme for adults with Down syndrome ($N = 12$; $M_{age} = 30$) without dementia. Participants were randomly assigned to CST ($n = 6$) or control (services as usual; $n = 6$), with assessments at baseline, post-programme, and four-month follow-up by a blinded researcher. **Results.** The adapted CST was feasible, with high attendance, strong satisfaction, and good fidelity (all >85%). CST participants showed significant gains in adaptive behaviour at post-programme, maintained at follow-up, and a trend toward improved episodic memory . **Conclusion.** Manualised group-based CST can be

successfully adapted for younger adults with Down syndrome and shows promise in supporting cognitive health for this population.

**Lay Summary**

- Nearly all adults with Down syndrome will develop brain changes caused by Alzheimer's disease starting in their 30s. While there is growing interest in understanding how cognitive exercises might support brain health in general, research specifically focused on this population is very limited.
- A 14-session cognitive stimulation therapy (CST) programme was adapted for a group of adults with Down syndrome, who were showing no signs of memory problems or dementia. The goal was to see if they enjoyed the program, took part in it, and if it helped their well-being, memory, and everyday skills.
- The CST programme was well-attended and the adults taking part reported high levels of satisfaction with the CST sessions.
- Participants showed gains in their memory, communication and daily living skills and this trend was not observed in the comparison group of adults who did not take part in the adapted CST programme. However, as only a small number of people were included in this comparison, more participants would be necessary for conclusive results.

## Introduction

Adults with Down syndrome are at “ultra-high” risk of developing Alzheimer’s disease (Pape et al., 2021) at a much younger age than the general population (Torr et al., 2010) likely due to overproduction of amyloid precursor protein from the extra copy of chromosome 21 (Fortea et al., 2022). Alzheimer’s disease neuropathology is almost universal in adults with Down syndrome by the age of 40 years (Lott et al., 2019). However, studies have consistently found that not all adults with Down syndrome appear to develop clinical signs of dementia (Head et al., 2012). In the general population, a discrepancy such as this may be explained by the concept of Cognitive Reserve (CR; Stern, 2002; Pucci et al., 2023) which refers to the brain's ability to adapt and compensate for damage or age-related changes. CR is developed throughout life and is influenced by activities that are cognitively stimulating (e.g., life experiences, participation in stimulating environments, and education) and that challenge the brain and foster the creation of new neural connections (Stern, 2009). People with higher CR may be able to tolerate more brain damage before cognitive symptoms, like memory loss, become apparent (Stern et al., 2020).

Advances in our understanding of cognitive reserve (Stern, 2002) and neuroplasticity (the brain’s ability to adapt or change over time, by creating new neurons and building new networks; Trojan & Pokorny, 1999) have provided a theoretical foundation for research to explore the association between increased cognitive stimulation and healthy brain ageing in younger adults with Down syndrome (Pucci et al., 2024; Mateos Villalón, 2023). For an adult

with Down syndrome, leading a cognitively stimulating life may buffer against the deleterious impact of the inevitable AD related neurodegeneration (Zigman & Lott, 2007), through bolstering cognitive reserve and supporting networked plasticity in brain areas activated during compensatory responses to acquired neuropathology (Head et al., 2016). A recent scoping review (see LaFace et al., 2023) found some evidence to indicate that stimulating lifestyle activities (such as community and social activities, employment activities and education) can positively influence cognitive functioning in people with Down syndrome.

At this point in time, however, evidence-based health promotion and disease prevention interventions to mitigate dementia risk in adults with Down syndrome remain scarce (Santos et al., 2022). There is some evidence that, for older adults in the general population, engaging in regular cognitively stimulating activities in later life (such as reading, writing, board games, playing cards) can delay the onset of Alzheimer's disease (e.g. Wilson, et al., 2021). Research on the benefit of cognitively stimulating activities for adults with Down syndrome, however, is very limited and has primarily focused on individuals already showing symptoms of dementia (e.g. Ali et al., 2023). Very few studies have explored the potential of proactive cognitive stimulation to preserve cognitive function in healthy adults with Down syndrome (Shanahan, 2014). To address this gap, a feasibility randomised control trial (RCT) was conducted to explore the acceptability and effectiveness of a group-based cognitive stimulation programme (Cognitive Stimulation Therapy; Spector et al., 2006, 2020) that we adapted for younger adults with Down syndrome who were showing no objective signs of memory loss or dementia.

Cognitive stimulation therapy (CST) is a structured and evidence-based programme specifically designed for individuals with mild to moderate dementia in the general population (Spector et al., 2003, 2020). The primary goal of CST is to enhance both cognitive and social functioning through group sessions that promote cognitive stimulation using a variety of

activities that encourage ‘new thinking’, reminiscing and social interaction. These activities are tailored to stimulate different areas of cognition and create an environment where participants can actively engage and learn (Spector et al., 2006). There are 18 key principles of CST (see Table 1) which should be met in each CST session to promote maximum engagement and cognitive stimulation (Spector et al., 2020, 2006). The standardised 7-week CST program consists of group sessions held twice a week (14 sessions), each lasting about an hour.

**Table 1.** *The 18 Key Principles of CST*

| | |
|---|---|
| 1. | **Mental stimulation:** Improving cognition and communication through mentally stimulating discussion. |
| 2. | **New ideas, thoughts and associations:** Encouraging new ideas and opinions by making new semantic connections. |
| 3. | **Using orientation, sensitively and implicitly:** Integrating orientation information into general discussion. |
| 4. | **Opinions rather than facts:** Using topics to generate opinions rather than testing facts. |
| 5. | **Using reminiscence as an aid to the here and now:** Comparing old and new to promote orientation. |
| 6. | **Physical movement:** Exercising motor skills through movement and games. |
| 7. | **Providing triggers and prompts to aid recall and concentration:** Supporting learning through multisensory cues and an information board. |
| 8. | **Continuity and consistency between sessions:** Using consistency of sessions to help continuity and familiarity. |
| 9. | **Implicit (rather than explicit) learning:** Let learning and remembering happen naturally. |
| 10. | **Stimulating language:** Promoting communication and conversation. |
| 11. | **Stimulating executive functioning:** Using activities to support planning and organising thoughts. |
| 12. | **Person-centred:** Seeing the person and their uniqueness. |
| 13. | **Respect:** Respect and dignity for all. |
| 14. | **Involvement and inclusion:** Keep everyone involved. |

| | |
|---|---|
| 15. | **Choice:** Activities are flexible and should be adapted for the participants. |
| 16. | **Fun:** Make it fun and enjoyable |
| 17. | **Maximising potential:** Optimise the learning environment to support people's potential. |
| 18. | **Building / strengthening relationships:** Becoming friends. |

Source: adapted from the CST manual; Spector et al (2020).

CST has been rigorously researched for individuals with mild to moderate dementia in the general population and there is strong evidence that CST leads to improvements in cognitive function (Woods et al., 2023) and quality of life (Chao et al., 2020) in this cohort. There is some evidence that CST also appears to be an implementable and acceptable programme for adults with Down syndrome showing signs of dementia (e.g. Ali et al., 2023).

We chose to adapt this programme as we could find no alternative group-based cognitive stimulation programme that we felt could be easily adapted for adults with Down syndrome. We used the UK Medical Research Council and National Institute for Health Research guidance on developing and evaluating complex interventions (Skivington et al., 2021) to frame our current study with a key focus on adapting an existing evidence-based programme for a different target group (younger adults with Down syndrome showing no objective signs of memory loss or dementia) and then assessing the feasibility and acceptability of this adapted programme in a 'real world' setting. We aimed to measure feasibility and acceptability in terms of recruitment and retention rate, barriers to participation, barriers to attending the CST programme, session satisfaction and engagement, CST programme fidelity, and the resource-cost of running this adapted CST programme within one community based intellectual disability service. A secondary aim was to assess the suitability of a randomised control trial design to measure the effectiveness potential of this adapted CST programme when compared to services as usual. We chose to measure gains in four outcome constructs (episodic memory, adaptive behaviour, memory self-efficacy, and perceived well-being) because of their

association with cognitive health in the general population (Wilroth et al., 2023; Mendonca et al., 2022; Beaudoin & Desrichard, 2016) and because gains in these constructs may lead to greater engagement in stimulating lifestyle activities for adults with Down syndrome.

## Method

### Design

A single-blinded feasibility randomised control trial design was used to evaluate the feasibility and effectiveness potential of an adapted CST programme (CST) versus services as usual (SAU) for adults with Down syndrome showing no objective signs of memory loss or dementia. We qualitatively evaluated the feasibility of this adapted CST programme with a focus on recruitment and retention, session satisfaction and engagement, CST programme fidelity, and resource-cost. Qualitative feasibility data was collected throughout the study period. Effectiveness measures of episodic memory, perceived well-being, memory self-efficacy and adaptive behaviour were completed at baseline (prior to randomisation), immediately following the CST programme, and at four-month follow-up by a researcher who was blinded to group (CST Vs SAU) membership. This study was approved by the [Institution; ID808] Research Ethics Committee, with all data collection conducted in accordance with the guidelines established via the Declaration of Helsinki (WMA, 2013).

### Participants

Participants were adults (i) aged 20 to 45 years, (ii) who had Down syndrome and a moderate intellectual disability (level of intellectual disability was determined based on formal psychological assessment in adulthood using *Diagnostic and Statistical Manual of Mental Health Disorders [*5th ed.; DSM–5; American Psychiatric Association, 2013] criteria for

diagnosis of moderate intellectual disability); (iii) who did not have significant behaviours of concern that would hinder group participation (e.g., no recent history of verbal or physical aggression or property destruction); (iv) who were able to consent to take part in this study and (v) who were showing no objective signs of memory loss or dementia as assessed by collateral interview at baseline by a doctoral-level clinical psychologist using the Dementia Scale for Down Syndrome (DSDS; Gedye, 1995). This screening was repeated at each assessment point to ensure participants remained free of observable signs of memory loss or dementia throughout the study.

**Recruitment**

Participants were recruited from one intellectual disability service provider in the Republic of Ireland which provides training, employment, social and residential programmes to approximately three hundred adults with moderate, severe and profound intellectual disabilities. Only adults with a moderate level of intellectual disability were recruited, as individuals with more severe impairments were less likely to be able to provide informed consent or engage with CST. The head of Psychology (who was not a member of the research team) determined which adults within this service were meeting criteria (i) – (iii) above. These adults were sent a brief 'easy read' letter (following European Easy-Read Standards; Inclusion Europe, 2010) detailing the study and were asked to contact an administrator (not a member of the research team) if they wanted to hear more about the study. The administrator obtained verbal consent to send an easy-read information pack and consent form, encouraged support from family or staff, and secured permission for follow-up. About a week later, the principal investigator contacted participants to address questions and assist with consent, providing a stamped envelope for returning forms.

Each participant nominated a proxy (staff, carer, or family member) during the consent process to provide collateral information confirming the absence of observable memory loss or dementia (via DSDS screening) and to complete adaptive behaviour measures. Proxies were not blinded to group allocation. Twelve adults (see Figure 1) and their respective proxies consented and completed the study in full.

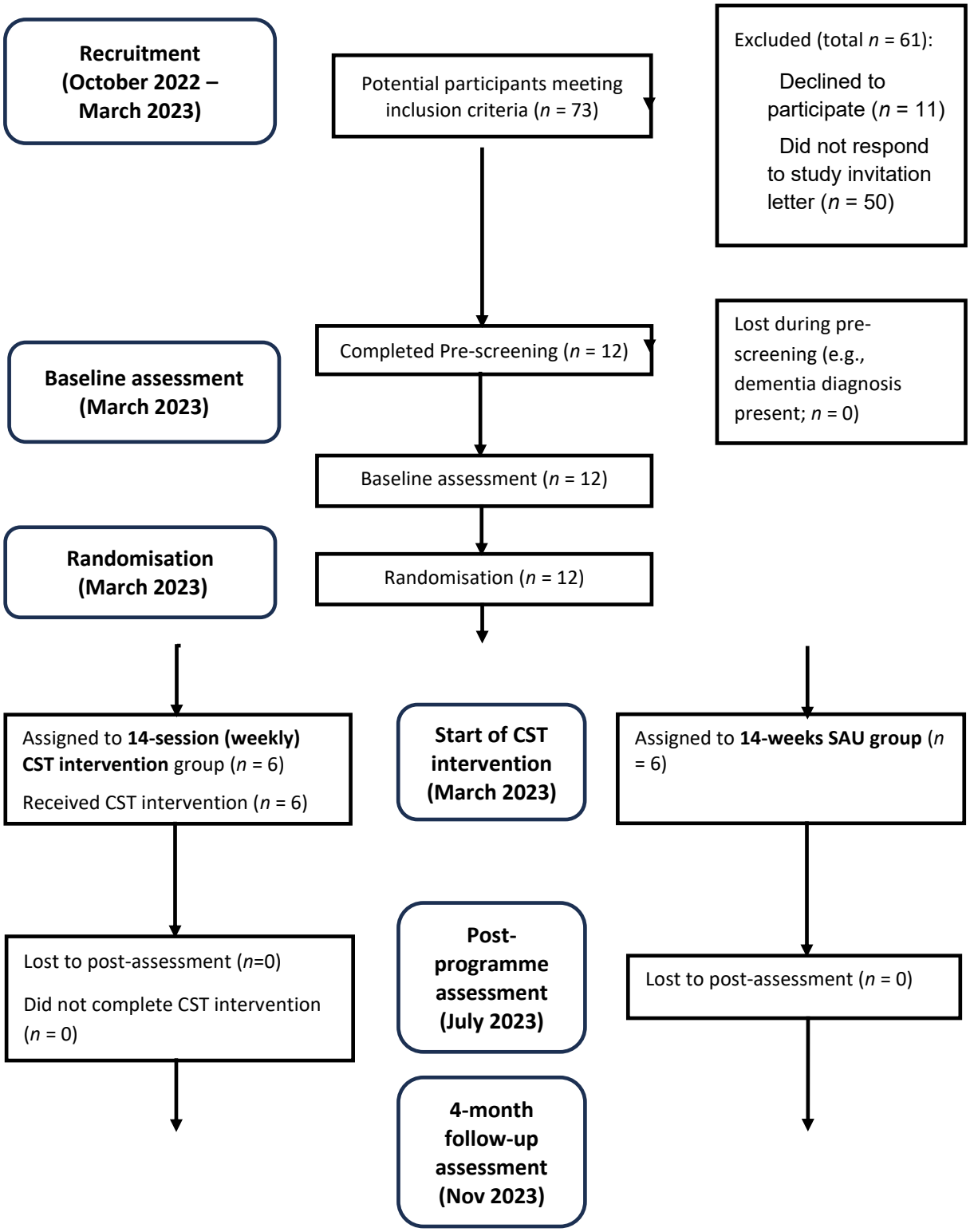


**Figure 1: Participant Flow Diagram.** CST = Cognitive Stimulation Therapy. SAU = services as usual.

**Randomisation**

After completing their baseline (pre) assessment, participants were randomly allocated to either the CST or SAU condition, with groups initially matched for gender (see Table 2 for demographics). Randomisation was conducted by a researcher not involved in data collection (FHS). To determine group membership, non-identifiable participant codes were generated, placed in a physical container, and drawn out at random.

**Table 2.** *Demographic Characteristics*

| | Sample ($N$ = 12) | |
|---|---|---|
| Characteristics | CST group ($n$ = 6) | SAU group ($n$ = 6) |
| Age (years) | | |
| Mean | 29.00 | 31.00 |
| SD | 6.29 | 10.58 |
| Range | 24 – 38 | 20 - 44 |
| Sex | | |
| Male (%) | 4 (66.7%) | 4 (66.7%) |
| Female (%) | 2 (33.3%) | 2 (33.3%) |
| Number of weekly activities* | | |
| Mean | 13.17 | 13.33 |
| SD | 2.14 | 3.50 |
| Range | 10 – 16 | 8 – 18 |
| Level of exercise** | | |
| Low (%) | 1 (16.7%) | 2 (33.3%) |
| Moderate (%) | 0 | 2 (33.3%) |

| | | |
|---|---|---|
| High (%) | 5 (83.3%) | 2 (33.3%) |

Note. *Each participant provided a copy of their weekly timetable which outlined their daily activities from Monday-Friday within the service. The number of weekly activities was calculated as the total number of activities the participant engaged in each week. Activities included a range of leisure, work, and cognitive activities (such as bowling, work experience, and computer class). Activities participants may have taken part in outside of day service hours in the evenings or at weekends were not included in this calculation.

**Participants' level of exercise was rated based on information provided by interviews at baseline assessment with participants and their proxy participants about participants' typical level of weekly exercise. This information was categorised by the researchers according to the criteria used by Pape et al., (2021). *High intensity* – exercise of an intensity greater than walking at least three times per week, or for at least three hours per week. *Moderate intensity* – exercise at an intensity equal to that of walking at least three times a week, or exercise < three hours a week/three times a week of an intensity greater than walking, or at least two hours a week of exercise where intensity or type was not specified, or a combination of walking and other exercise when duration or intensity not specified. *Low intensity* – all exercise not meeting the above thresholds, including individuals who do not engage in any exercise.

## Adapting and delivering CST for adults with Down syndrome

Prior to delivering the CST programme, facilitators attended an accredited one-day CST training workshop. Before attending the CST group, participants, with support from their proxy, completed an 'information sheet' covering their interests, favoured activities, familiar areas, dislikes, communication abilities, and support needs. This helped ensure a person-centred approach in planning sessions.

CST sessions were adapted from the 'Making a Difference' manual (Spector et al., 2020) and followed the standard fourteen session topics (one topic per session) as outlined in this manual (see Table 3). Activities were adapted with a person-centred approach, tailored to participants' unique interests (e.g., music, sports, hobbies) and abilities (e.g., talents, strengths). This ensured that activities and news items were engaging and promoted active participation and enjoyment. Session materials followed the European Easy-Read Standards ('easy read'; Inclusion Europe, 2010) to promote understanding and engagement. Cognitively complex activities (e.g., Session 11 'using money') required more adaptation and simplification, while simpler activities (e.g., Session 1 'physical games') needed little to no adaptation (see Table 4 for main activity adaptations). Canva Pro (a graphic design platform that provides tools for

creating visual materials and resources) was used to assist in designing 'easy read' materials for the CST session activities.

CST sessions were delivered in a fun, socially interactive, and relaxed manner, encouraging 'new thinking' throughout. Sessions followed a consistent structure (see Table 3), lasting 60-75 minutes, including three research measures. Most activities, except the 'group song,' required more time than suggested in the CST Manual (Spector et al., 2020). After each CST session, facilitators held a 30-minute planning meeting to review what worked well, identify necessary material adaptations, address challenges with the key principles, and plan for the next session. They also discussed upcoming topics and gathered participant-specific information (e.g. for Session 10 'Orientation' – focus on landmarks and locations in Ireland and abroad that participants were familiar with) from keyworkers, if needed. Weekly planning meetings, attended by the research team, were held every Monday to finalise session activities, make adaptations based on participant preferences and previous engagement, and determine how to target the 18 key principles (see Table 1).

The 14-session CST programme was delivered weekly over 14 weeks in a spacious therapy room by a Clinical Psychologist (AR) and Occupational Therapist (MK), with occasional support from a Speech and Language Therapist (LH) during facilitator absences. This weekly format, adapted from the standard twice-weekly model, was based on participant feedback to support better attendance.

**Table 3.** *Structure of adapted CST Sessions*

| Session activity | Duration | Adaptation(s) |
|---|---|---|
| Welcome | 5 mins | A visual schedule was displayed on the white board and referenced at the end of the Welcome activity. This schedule displayed one common image/sign to represent each session activity. This helped participants to understand the sequence of activities at each session. As each activity was completed the image/sign for that activity was moved to the 'finished box'. |

| | | |
|---|---|---|
| | | Participants took turns to move the images to the finish box to encourage participation and movement. |
| Group Song | 5 mins | None |
| Orientation | 10 mins | Easy read materials were developed to aid participation and recall. Day/Date/Time/Weather/Season were discussed, one at time, with accompanying 'easy read' visual/verbal signs to augment verbal discussions on these topics and to aid participation and recall. |
| News Item | 10 mins | Each week two topical news items that were deemed likely to be of interest to participants (based on their personal preferences information) were agreed prior to the session. An 'easy read' sheet in the style of a newspaper or magazine page was created for each news item to aid recall and participation in this activity. Whenever possible, recent news items involving people with Down syndrome were included (e.g. "James Martin, the First Actor with Down Syndrome to Win an Oscar"). |
| Ball Game | 8 mins | None |
| Main Activity A | 20 mins | See Table 4 for full details. |
| Main Activity B | 10 mins | See Table 4 for full details. |
| *Evaluation* | *5 mins* | *This is not part of the standard CST Manual. This activity was added in for the purpose of collecting research data.* |
| Close | 2 mins | None |
| Refreshments | 5 mins | 'Refreshments' was moved to the end of the session. In the CST manual 'refreshments' take place after 'news item'. However, CST facilitators found it worked better to leave this activity to the end of the session. When located in the middle of the session, they found it was very difficult to move participants on from this activity within the allotted time (5 mins) and this led to the main activity being cut short. This change was made from Session 2 onwards. |

* Source: CST Manual (Spector et al., 2020)

**Table 4.** *Adaptations to Main Activities by Session*

| **Session** | **Topic** | **Main Activity A** | **Main Activity B** |
|---|---|---|---|
| 1 | Physical games | No adaptation | No adaptation |
| 2 | Sounds | No adaptation | No adaptation |
| 3 | Childhood | The record sheet (p.26) for this task was simplified and presented in 'easy read' format. Participants were offered support with writing answers during the session, if needed. | Focus on childhood toys from the 1980s/1990s/2000s due to younger age range of our group. Childhood sweets not targeted due to time constraints. |

| | | | |
|---|---|---|---|
| 4 | Food | Clear large pictures of food items and actual food items were used to aid participation and recall for this activity. Focus on concrete and familiar categories, e.g. dinner versus breakfast. | Food tasting foods were highly contrasted (e.g. sweet versus sour) to encourage participation/reaction. Easy chew/swallow foods were chosen to ensure all participants could fully take part (as some required modified diet/consistency). |
| 5 | Current affairs | News items that were deemed likely to be of interest to participants (based on their personal preferences information) were agreed prior to the session. An 'easy read' sheet in the style of a newspaper or magazine page was created for each chosen news item to aid recall and participation in this activity. | Three 'easy read' cue cards were created to stimulate conversation on news, views, attitudes, dreams and aspirations. |
| 6 | Faces/scenes | No adaptation to faces activity. Scenes were chosen that would be familiar to participants and encourage reminiscence (e.g. childhood locations such as school, sports pitch etc.). | No adaptation |
| 7 | Word association | Phrases that participants were likely to be familiar with were chosen. These were represented in large written font with clear visual prompts for missing words. Visual prompts for key words in these phrases were provided if needed. | Songs that participants were likely to be familiar with were chosen. Key song lyrics were represented in large written font with clear visual prompt for the missing word. A clip of each song was played and stopped before the missing word was sung. Participants then took turns to complete the lyric. They were encouraged to sing the chorus of the song together if they wanted. |
| 8 | Being creative | Focus on gardening task. Easy read instruction sheet developed to aid participation in this task (potting a plant). | No Activity B for this session in manual. |
| 9 | Categorising objects | Actual physical objects used. Categories chosen that participants were likely to be very familiar with. | Clear pictures of familiar objects used. Categories chosen that participants were likely to be very familiar with. No other adaptation. |
| 10 | Orientation | Local landmarks presented visually (one image per page). | Focus on childhood and recent holidays/travel. Large colourful |

| | | | |
|---|---|---|---|
| | | Large map of Ireland and County displayed. Focus on landmarks and locations that participants were familiar with. | map of world displayed to aid participation and recall. Focus on holiday destinations that participants were familiar with to aid participation and reminiscence. |
| 11 | Using money | Actual items displayed that participants were likely to have purchased. Actual money (coins/notes) displayed to aid participation. | Clear visual images used (one item per page) and highly contrasted (e.g. car versus loaf of bread) with focus on 'cheap' versus 'expensive'. We did not focus on 'old' versus 'new' currency (e.g. punt versus euro) as our participants were young adults and so less likely to have experience of 'old' currency. |
| 12 | Number games | Accessible Bingo score sheet used with large numbers. No other adaptations. | Large visual of playing cards (one playing card per A4 sheet used) used to play 'higher' or 'lower' as per manual. |
| 13 | Word games | Eight familiar word pairs presented with one key word missing in 'easy read' format. Participants asked to guess the missing word (e.g. 'Buckingham …?' with clear visual of Buckingham Palace). | An adapted 'easy read' word search sheet was created with words that participants were likely to know. Support offered to participants with reading/word searching if needed. |
| 14 | Team quiz | Clear 'easy read' visuals of six previous session activities (that CST Facilitators felt got the best reaction/engagement) were presented and discussed by the group. | Presentation of Group Completion Certificate to each group member. |

* Source: CST Manual (Spector et al., 2020)

**Feasibility Measures**

**Recruitment rate** was calculated as the proportion of participants recruited from the total eligible pool, along with the average monthly recruitment rate. **Barriers to participation** were recorded for potential participants who declined to join the study and had given verbal consent for follow-up contact by the principal investigator. **Retention rate** was calculated as the number of individuals that completed the follow-up measures as a proportion of those recruited. **Attendance** was recorded at each of the 14 CST sessions. **Barriers to attendance**

was the reason given by participants for their absence from session(s). The behavioural approaches taken by CST Facilitators to address these barriers and encourage future attendance were also recorded.

**Session satisfaction** was recorded at the end of each CST session using a picture-based 'easy read' scale, developed by the research team. Participants rated their satisfaction on a 5-point Likert scale (from '0' = '*No!*' to '5' = *'Yes a lot!*'; higher scores indicating greater satisfaction) in terms of enjoyment (did you enjoy this class?), helpfulness (was this class helpful?), willingness to attend again (do you want to come to your next class?), and likelihood to recommend to a friend (do you think your friend would find this class helpful?).

**CST Programme Fidelity** was recorded at the end of each session by CST Facilitators who discussed each of the 18 key principles of CST (see Table 1; adapted from Spector et al., 2020) and whether these were present, or absent, during each session. They then completed the '18 Key CST Principles checklist', developed by the research team, to document the presence or absence of each CST principle at each session.

**Level of engagement per session** was rated by CST Facilitators at the end of each session by completing a "Monitoring Progress" evaluation form (adapted from the CST Manual, pg. 18; Spector et al., 2020). This form allowed CST facilitators to rate participants' level of engagement during each session across four domains; level of interest, communication, enjoyment, and mood (range; 0 – 4; with higher scores indicating greater interest, communication, enjoyment, and better mood). This form included space for CST facilitators to provide written feedback on each session and suggest adaptations for future activities.

The **resource-cost** of running the adapted CST programme in one community-based intellectual disability service was calculated by recording number of hours it took from adaptation to completion and itemising equipment costs where possible. The **acceptability of**

**the outcomes measures** was measured in terms engagement/understanding, completion time and completion rate.

**Efficacy Measures**

**Cognitive function (episodic memory).** The modified FULD Object Memory Evaluation (FULD; Aylward et al., 1997) was conducted as a measure of episodic memory. The FULD has been found to be a reliable and valid measure of episodic memory (with reliability coefficients ranging from 0.91 to 0.96; Chung, 2009) and is currently recommended for use in dementia screening among adults with intellectual disabilities (College of Psychiatrists of Ireland, 2014). Form I and Form II were alternated at each assessment period (i.e. Baseline – Form I; Post-assessment – Form II; Follow-up – Form I) to reduce the likelihood of a practice effect. Retrieval was calculated by summing the total number of items recalled across the five recall and delay trials (trials 1 – 5 + delay). Repeated retrieval was calculated by summing the total number of items repeatedly retrieved across the five recall and delay trials (trials 1 – 5 + delay).

**Cognitive function (verbal fluency).** Between each FULD recall trial (Aylward et al., 1997) participants also completed a distractor task which involved naming as many words as possible, in 30 seconds, from five categories (e.g., items you can buy in a supermarket). The number of items recalled during this 'distractor' task was used as a measure of verbal fluency. Verbal fluency was calculated by summing the total number of words named across all five distractor tasks (5 categories x 30 seconds).

**Adaptive behaviour.** The Vineland Adaptive Behaviour Scales 3rd edition Domain-Level Parent/Caregiver Form (Vineland; Sparrow et al., 2016) was completed by proxy participants to measure participants' adaptive behaviour. The Vineland is a valid and reliable

(Cronbach alpha scores range from 0.95 to 0.99) measure of the personal and social skills needed for everyday living (Sparrow et al., 2016).

**Subjective wellbeing.** Subjective wellbeing was measured using the Personal Wellbeing Score (PWS; Benson et al., 2019) that we adapted for this study to make it more 'easy read'. The PWS has been shown to have good psychometric properties (Cronbach's alpha > 0.80; Benson et al., 2019). Adaptations to the PWS were made by the research team in collaboration with two adults with moderate intellectual disabilities and a Speech and Language Therapist, to maximise the accessibility of the PWS for the participants. Participants responded to the adapted PWS questions using a simplified 'easy read' 5-point Likert scale (range; '0' = '*Disagree a lot*' to '4' = '*Agree a lot*'), with higher scores indicating greater subjective wellbeing. A PWS summary score on a 16-point scale was calculated by adding participant scores across all four items (range '0' = lowest possible subjective wellbeing to '16' = highest possible subjective wellbeing).

**Memory self-efficacy.** Memory self-efficacy was measured using a self-rated 7-item scale that was developed for this study by the research team. The 7-item scale included one general memory question to capture participants' overall subjective confidence in their memory ability. Six frequency of forgetting items were developed based on the Frequency of Forgetting-10 (FOF-10; Zelinski & Gilewski, 2004) scale and the DSDS (Gedye, 1995). Specific items from the FOF-10 and DSDS were selected based on their perceived relevance to the everyday lives of adults with Down syndrome. This measure was constructed by the research team in collaboration with two adults with moderate intellectual disabilities and a Speech and Language Therapist, to maximise the accessibility of this measure for the participants. Participants responded to the 7-item memory self-efficacy scale using a simplified 'easy read' 5-point Likert scale (range '0' = '*very bad*' to '4' = '*very good*' for the general memory question; and range; '0' = '*everyday*' to '4' = '*never*' for the FOF-10 items), with

higher scores indicating greater memory self-efficacy. A mean memory self-efficacy item score was calculated (range; '0' = lowest possible memory self-efficacy to '4' = highest possible memory self-efficacy) by dividing participants' total score across all items (1 – 7) by 7 (number of items).

### Data Analysis

Descriptive statistics were conducted to describe feasibility outcomes of the study. Between-group comparisons (CST vs SAU) were performed at baseline, post-programme, and four-month follow-up using the non-parametric Mann-Whitney *U* test. Within-group comparisons were conducted using the non-parametric Friedman test which provided a global measure of change across the three time-points (baseline, post-programme, and four-month follow-up). To conduct pairwise comparisons for variables showing significant change over time, the Friedman analyses were supplemented with post-hoc Wilcoxon signed-rank tests which helped identify any statistically significant associations between each timepoint (e.g., from baseline to post-programme and post-programme to four-month follow-up). All statistical tests were performed using IBM SPSS Statistics Version 29 software.

## Results

### Feasibility Findings

### Recruitment rate

Of the 73 potential participants who were each sent a study invitation letter, 50 (69%) did not respond to this invitation and 23 (31%) did respond noting their initial interest in the study. After receiving more information about the study, including an 'easy read' information pack and consent form, 11 (15%) declined to participate (see Table 5 for details on barriers to participation) and 12 (16%) consented to participate. This led to a recruitment rate of 16%.

Recruitment was open for four months, so on average, 3 participants were recruited to this study per month.

**Table 5.** *Barriers to participation*

| **Reasons for not participating** | ***N* = 61** |
|---|---|
| Did not respond to study invitation | 50 (82%) |
| Primary caregiver unwell/unavailable | 5 (8%) |
| Potential participant could not consent (unable to understand the information pack) | 3 (5%) |
| Potential participant did not want to take part | 2 (3%) |
| Potential participant unavailable | 1 (2%) |

**Retention rate**

All recruited participants ($N$ = 12) attended for assessment at baseline (March 2023), post-programme (July 2023) and four-month follow-up (November 2023). All proxy participants ($N$ = 12) completed assessments at baseline, post-programme and four-month follow-up. This led to a retention rate of 100% for participants and proxy participants.

**Attendance**

On average, participants in the CST group ($n$ = 6) attended 12 out of 14 sessions (86%; $M$ = 12 sessions; $SD$ = 1.67; range 10 – 14). Reasons given for non-attendance and behavioural approaches used by CST facilitators to promote future attendance are detailed in Table 6.

**Table 6.** *Barriers to attendance and behavioural approach to promote future attendance*

| Reasons given for not attending | *N* = 12 classes/ 5 participants | Behavioural approach taken by CST facilitators to promote future attendance |
|---|---|---|
| Pre-booked holidays | 9 classes/5 participants | None |
| Participant chose to attend a different activity outside of the service instead of attending their CST class | 1 class | None |
| Staff transport error | 1 class | Phoned staff and agreed strategy to ensure this won't happen again |
| Participant attended day service instead of CST class by mistake | 1 class | Phoned participant and proxy participant to remind them of the day/time of the next CST session |

**Session Satisfaction**

Participants displayed an overall high level of satisfaction (rating scale 0 – 5) with CST sessions (mean item score across all attended sessions = 4.75, *SD* = .34; range 4.10 – 5.00). Responses to the four session-satisfaction questions, expressed as percentages of total responses across Sessions 1–14, are presented in Figures 2, 3, 4, and 5.

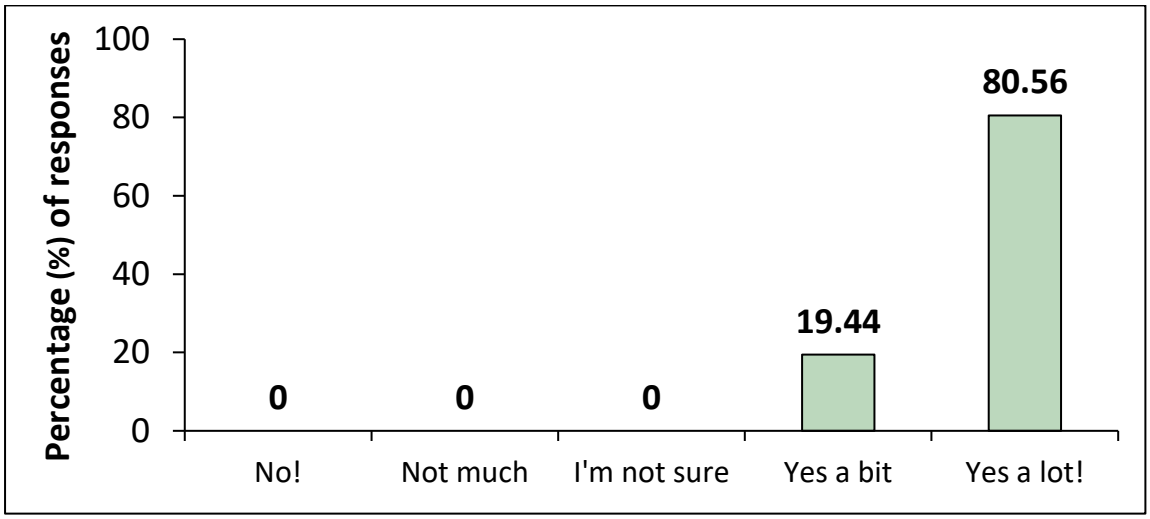

**Figure 2.** *Participant Satisfaction Scores as Percentages to Question 1: "Did you enjoy this class?".*

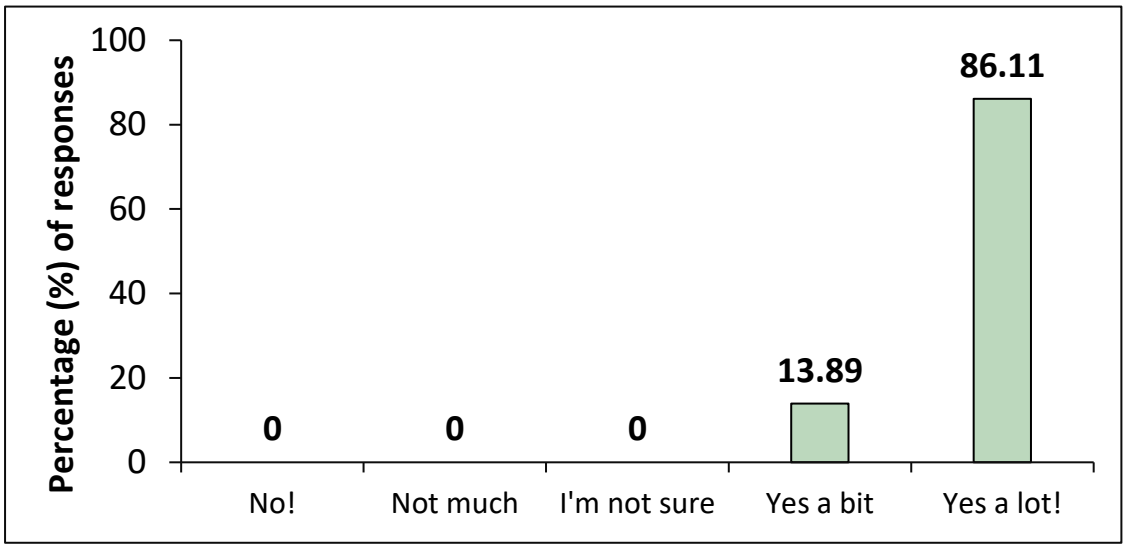


**Figure 3.** *Participant Satisfaction Scores as Percentages to Question 2: "Was this class helpful?".*

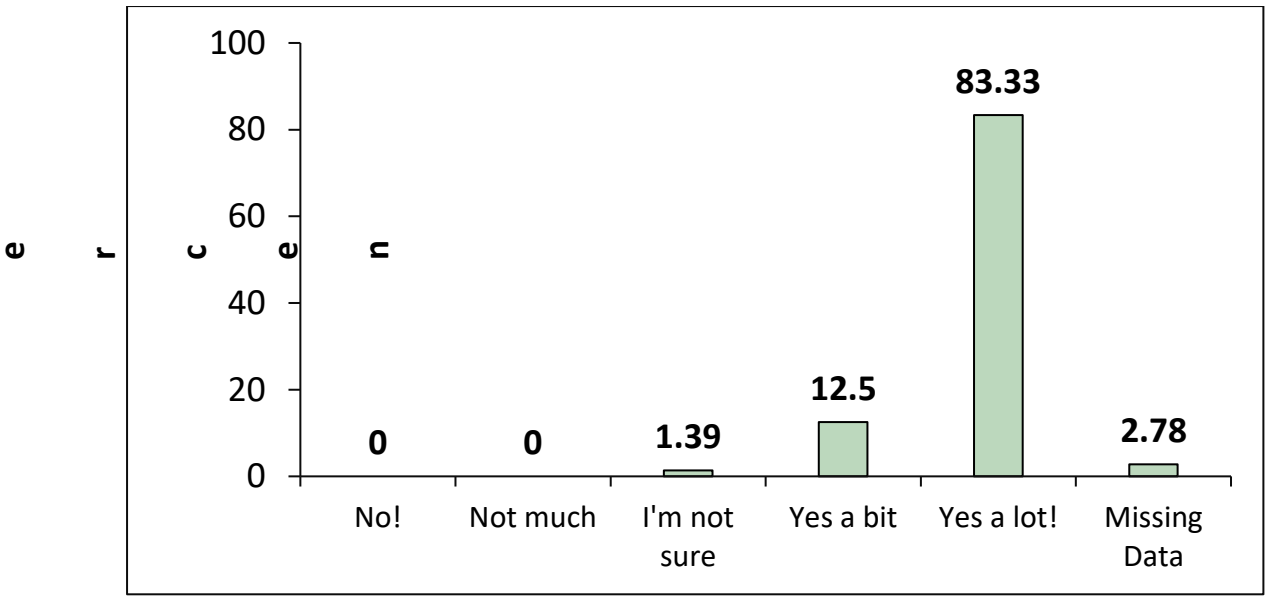


**Figure 4.** *Participant Satisfaction Scores as Percentages to Question 3: "Do you want to come to your next class?".*

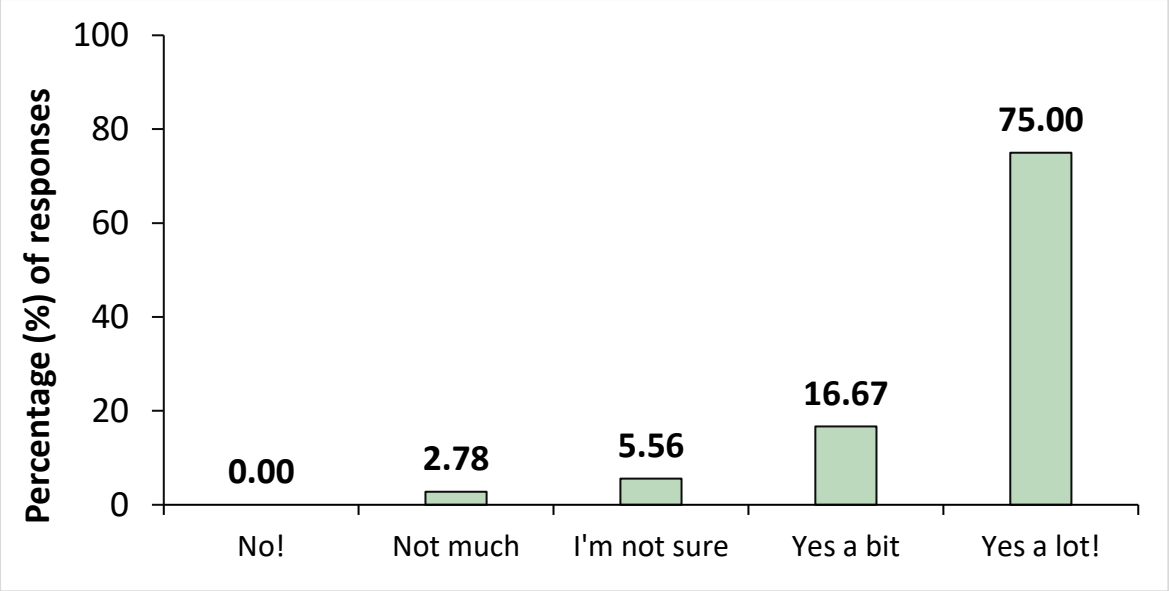


**Figure 5.** *Participant Satisfaction Scores as Percentages to Question 4: "Do you think your friend would find this class helpful?".*

**CST Programme Fidelity**

All 18 key CST principles (see Table 1) were met in 10 out of 14 sessions, and at least 16 out of 18 key principles (89%) were achieved in all 14 sessions. There were only two principles ('using reminiscence as an aid to the here and now' and 'physical movement') that were not present in all 14 CST sessions. Difficulty incorporating 'physical movement' was noted in Session 6 and 8 and difficulties 'using reminiscence as an aid to the here and now'' was noted in Session 2 and 6.

**Participant engagement per session**

Facilitator ratings of participant engagement per session were high across all domains (rating scale 0 – 4); interest (*M* = 3.66, *SD* = .29), communication (*M* = 3.66, *SD* = .34), enjoyment (*M* = 3.54, *SD* = .34), and mood (*M* = 3.63, *SD*= .21). Facilitator's ratings on the four domains are presented below in Figure 6. Percentages were calculated using the mean facilitator rating for each variable (e.g., interest, communication, enjoyment, mood) across all sessions (1 – 14).

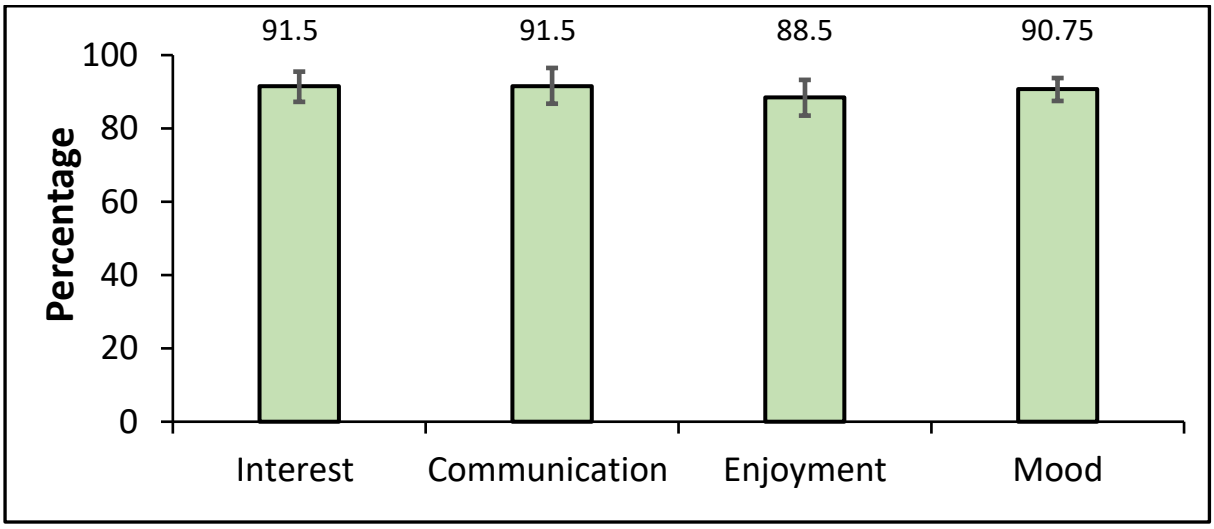


**Figure 6.** *CST Facilitator Rating Scores as Percentages. Note.* Error bars represent 95% confidence intervals.

**Resource-cost of the adapted CST programme**

It took a total of 100 hours to adapt and run the CST programme from start to finish (see Table 7 for breakdown of hours). The equipment that was needed to adapt and run this CST programme is itemised in Table 8.

**Acceptability of outcome measures**

The three participant outcome measures (modified FULD, subjective wellbeing, memory self-efficacy) took 40-65 minutes to complete and were finished in one sitting at each assessment (pre, post, follow-up). Participants engaged well and understood the measures. No ceiling or

floor scores were observed at any timepoint, and there was no missing data for in-person measures. All proxy outcome measures (adaptive behaviour) were completed and returned, with reminders sent when necessary. Missed items were addressed via phone call with the proxy participant.

**Table 7.** *Number of hours required to adapt and run the CST programme*

| **Adapting and running the CST programme** | **Number of hours** |
|---|---|
| Two CST facilitators attended 1-day certified CST training | 14.0 |
| Pre-planning meeting: 30 mins per week over 14 weeks x two CST facilitators | 14.0 |
| CST Group including evaluation, set-up/clean-up: 90 mins over 14 weeks x two CST facilitators | 42.0 |
| Post-planning meeting: 30 mins per week over 14 weeks x two CST facilitators | 14.0 |
| Adapting/sourcing materials: 70 mins per week over 14 weeks | 16.3 |
| Total number of hours needed to adapt/run the CST Programme | 100.3 |
| Total number of hours per CST participant | 16.7 |
| Total number of hours per CST session | 7.2 |

**Table 8.** *Equipment recommended/needed to run the adapted CST programme*

| **Equipment recommended (CST Manual)** | **Adaptations/additional equipment/cost** |
|---|---|
| A device that can connect to the Internet to access websites such as YouTube. | None (used mobile phone available within service) |
| Printer and paper | None (available within service) |
| Whiteboard and pens | None (available within service) |
| Soft ball | None (available within service) |
| Song books | Developed ‘easy read’ song lyrics using computer/internet (available within service) |

| | |
|---|---|
| Skittles/indoor bowls/boules | None (available within service) |
| Old fashioned toys | Focus on toys from 1990s/2000s; found these at home/in attics |
| Box of non-perishable groceries | None (brought in from home with some items purchased at a cost of approx. €15) |
| Photographs of local scenes – past and present | None (sourced from internet; non-copyrighted images only) |
| A large map of the country | None (sourced from internet; non-copyrighted images only) |
| Photographs of famous faces | None (sourced from internet; non-copyrighted images only) |
| Digital camera and printer | None (available within service) |
| Trivia quiz books | Developed 'easy read' word searches using computer/internet and printed on A4 paper |
| Dominoes, playing cards, bingo | None (available within service) |
| Access to photocopier and laminator | None (available within service) |
| - | Bluetooth speaker (available within service) |
| - | Potting a plant task (purchased seeds, pots, compost, at a cost of approx. €10) |
| | Canva Pro (available within service) |

Source: adapted from the CST manual; Spector et al (2020).

**Efficacy Findings**

The CST and SAU groups were homogenous in terms of gender, age, and weekly activities ($p > 0.05$) [see Table 2]. Mean scores for both groups at baseline, post-programme, and four-month follow-up are shown in Table 9.

**Table 9.** *Mean scores (standard deviation) at pre, post and four-month follow-up.*

| | Sample ($N$ = 12) |
|---|---|

| Outcome Variable | CST ($n$ = 6) | | | SAU ($n$ = 6) | | |
|---|---|---|---|---|---|---|
| | Baseline | Post-programme | 4-month follow-up | Baseline | Post-programme | 4-month follow-up |
| **Cognitive Function** | | | | | | |
| ***(Episodic memory)*** | | | | | | |
| FULD Retrieval | 44.67 (7.09) | 47 (8.60) | 50.00 (8.27) | 38.83 (8.13) | 37.17 (4.45) | 45.50 (7.87) |
| FULD Repeated Retrieval | 30.67 (8.16) | 33.67 (9.52) | 36.50 (9.73) | 26.00 (6.81) | 24.5 (3.08) | 32.00 (8.49) |
| ***(Verbal fluency)*** | | | | | | |
| FULD Verbal Fluency | 28.83 (12.59) | 32.00 (18.44) | 35.83 (18.28) | 27.17 (13.93) | 28.00 (13.68) | 31.17 (14.63) |
| **Adaptive Behaviour** | | | | | | |
| Vineland Communication | 77.33 (9.73) | 81.00 (9.86) | 81.83 (10.83) | 59.83 (14.22) | 58.00 (18.11) | 57.67 (15.41) |
| Vineland Daily Living Skills | 76.00 (7.56) | 76.67 (11.93) | 77.67 (16.84) | 60.50 (17.25) | 62.00 (17.70) | 55.50 (18.62) |
| Vineland Socialisation | 79.00 (9.78) | 82.00 (10.64) | 86.17 (12.54) | 72.67 (9.75) | 69.33 (7.76) | 64.50 (14.00) |
| Vineland Composite Score | 75.17 (5.56) | 77.83 (8.66) | 80.17 (12.19) | 64.67 (10.48) | 63.50 (11.64) | 60.50 (12.18) |
| Vineland Physical Activity* | 37.33 (5.72) | 39.00 (5.62) | 41.67 (4.50) | 32.00 (11.22) | 32.67 (8.50) | 31.17 (12.37) |
| **Subjective Wellbeing** | | | | | | |
| 4-item PWS scale (Mean Summary Score; range 0 – 16) | 13.33 (1.75) | 11.33 (2.73) | 12.17 (2.14) | 11.17 (2.04) | 12.00 (4.15) | 11.17 (2.48) |
| **Memory Self-efficacy** | | | | | | |
| 7-item MSE scale (Mean Item Score; range 0 – 4) | 2.67 (.88) | 3.05 (.62) | 2.81 (.77) | 2.67 (.68) | 2.45 (.93) | 2.40 (1.18) |

Note. Data is reported above as mean group score (standard deviation). *Mean group *raw score* reported for Vineland Physical Activity domain (as no standard scores are available for Physical Activity domain in the Vineland manual). Scores for all other Adaptive Behaviour domains (e.g., communication, daily living skills, and socialisation) are represented as mean group *standardised scores*.

### *Between-group comparisons (CST Vs SAU at baseline, post-assessment, and follow-up).*

Between-group comparisons (CST vs SAU) showed no significant differences at baseline ($p$ > 0.05; see Table 10). At post-assessment, the CST group had significantly higher communication and overall adaptive behaviour composite scores than the SAU group. At the four-month follow-up, the CST group had significantly higher communication, socialization, and overall adaptive behaviour composite scores compared to the SAU group. No other significant between-group differences were found.

**Table 10.** *Between group comparisons (at baseline, post-programme, four-month follow-up)*

| | Baseline | | | Post-programme | | | Four-month follow-up | | |
|---|---|---|---|---|---|---|---|---|---|
| Outcome Variable | Mann-Whitney *U* statistic | *p* | Standardised test statistic | Mann-Whitney *U* statistic | *p* | Standardised test statistic | Mann-Whitney *U* statistic | *p* | Standardised test statistic |
| **Cognitive Function** | | | | | | | | | |
| ***(episodic memory)*** | | | | | | | | | |
| FULD Retrieval | 11.0 | .31 | -1.13 | 7.00 | .09 | -1.77 | 12.00 | .39 | -.96 |
| FULD Repeated Retrieval | 15.0 | .70 | -.48 | 8.00 | .13 | -1.61 | 13.00 | .49 | -.80 |
| ***(verbal fluency)*** | | | | | | | | | |
| FULD Verbal Fluency | 17.5 | 0.94 | -.08 | 14.50 | .59 | -.56 | 14.50 | .59 | -.56 |
| **Adaptive Behaviour** | | | | | | | | | |
| Vineland Communication | 6.0 | .07 | -1.94 | 4.00 | **.03*** | -2.25 | 4.00 | **.03*** | -2.24 |
| Vineland Daily Living Skills | 6.5 | .07 | -1.85 | 8.50 | .13 | -1.52 | 6.00 | .07 | -1.92 |
| Vineland Socialisation | 11.0 | .31 | -1.14 | 6.00 | .07 | -1.93 | 5.00 | **.04*** | -2.09 |
| Vineland Composite Score | 7.50 | .09 | -1.68 | 5.00 | **.04*** | -2.09 | 4.00 | **.03*** | -2.24 |
| Vineland Physical Activity | 13.5 | .49 | -.72 | 9.00 | .18 | -1.47 | 8.50 | .13 | -1.52 |
| **Subjective Wellbeing** | | | | | | | | | |
| 4-item PWS scale | 7.0 | .90 | -1.83 | 24.50 | .31 | 1.05 | 15.50 | .70 | -.41 |
| **Memory Self-efficacy** | | | | | | | | | |
| 7-item MSE scale | 14.5 | .59 | .56 | 11.50 | .31 | -1.05 | 15.50 | .70 | -.40 |

Note. Data is reported as: (i) first column; Mann-Whitney *U* test statistic, (ii) second column; two-sided exact *p* value and (iii) third column; the standardised test statistic. *****Indicates statistically significant between group differences (higher scores in CST group compared to SAU group) as assessed using a Mann-Whitney *U* test, $p < 0.05$.

### *Within-group comparisons*

For the CST group, FULD retrieval scores increased non-significantly from baseline to post-programme ($Z = 1.86$, $p = 0.06$) and significantly from post-programme to follow-up ($Z = 2.03$, $p < 0.04$). For the SAU group, scores did not increase from baseline to post-programme ($Z = -0.822$, $p = 0.41$) but increased significantly from post-programme to follow-up ($Z = 1.99$, $p <$

0.04). Median FULD retrieval scores were: CST (baseline = 45.0, post-programme = 48.5, follow-up = 51.5) and SAU (baseline = 40.0, post-programme = 38.0, follow-up = 47.5). No other significant within-group differences were found (see Table 11).

**Table 11.** *Friedman test scores (comparing baseline, post-programme, follow-up)*

| | CST (*n* = 6) | | SAU (*n* = 6) | |
|---|---|---|---|---|
| **Outcome Variables** | $X^2$ | ***P*** | $X^2$ | ***p*** |
| **Cognitive Function (Episodic memory)** | | | | |
| FULD Retrieval | 10.57 | **.005*** | 6.33 | **.04** |
| FULD Repeated Retrieval | 5.82 | .06 | 4.33 | .12 |
| FULD Verbal Fluency | 2.38 | .30 | 3.22 | .20 |
| **Adaptive Behaviour** | | | | |
| Vineland Communication | 4.33 | .12 | 1.65 | .44 |
| Vineland Daily Living Skills | 1.13 | .57 | 4.96 | .08 |
| Vineland Socialisation | 2.70 | .26 | 5.48 | .07 |
| Vineland Composite Score | 1.13 | .57 | 4.33 | .12 |
| Vineland Physical Activity* | 1.46 | .48 | 1.13 | .57 |
| **Subjective Wellbeing** | | | | |
| 4-item PWS scale | 4.78 | .09 | 2.00 | .37 |
| **Memory Self-efficacy** | | | | |
| 7-item MSE scale | 1.00 | .61 | .09 | .96 |

Note. $X^2$ refers to the test statistic and *p* refers to the 2-sided significance value. * Denotes associations between study variables that retained statistical significance after performing a Bonferroni correction.

## Discussion

The primary aim of the study was to assess the feasibility of delivering a group-based, manualised Cognitive Stimulation Therapy (CST) programme specifically adapted for adults with Down syndrome showing no objective signs of memory loss or dementia. A secondary aim was to evaluate the suitability of the randomised controlled trial (RCT) design and

assessment protocol, as well as to explore the programme's potential effectiveness in comparison to services as usual.

Feasibility indicators were largely favourable. The study achieved a high retention rate (100%), with strong attendance across CST sessions (86%), and high session satisfaction reported by participants (95%). Facilitators also provided encouraging ratings of participant engagement during sessions: interest (92%), communication (92%), enjoyment (89%), and mood (91%). Programme fidelity was assessed based on the presence of 18 key CST principles (see Table 1), with results indicating that all principles were achieved in most sessions (89%). These findings support the feasibility of conducting a larger-scale RCT which would benefit from the inclusion of independent ratings of participant engagement and treatment fidelity. A notable concern was the low recruitment rate (16%, averaging 3 participants per month), which may present a barrier to scaling up the study.

Recruitment challenges in research involving adults with intellectual disabilities are well documented (Bishop et al., 2024; Cooper et al., 2016). In this study, the primary barrier was that most eligible adults (69%) did not respond to the initial postal invitation. Due to ethical and data protection concerns within the service, researchers were unable to follow up directly with potential participants, which likely limited recruitment. Adults with intellectual disabilities express a clear desire to be involved in research (Bishop et al., 2024) and evidence suggests that a more personalised recruitment approach is often needed to facilitate their participation (Lennox et al., 2005; Nicholson et al., 2013). Future studies must carefully navigate this need within the boundaries of current data protection and capacity regulations. Another challenge arose during the informed consent process, with some potential participants finding the study information and consent materials difficult to understand. While 'easy read' formats are widely used, and were carefully implemented in the current study, they may not always be sufficient. Alternatives such as video-based information packs, though more

resource-intensive, may provide a more accessible and engaging method of delivering study information (Swaine et al., 2011). The involvement of people with intellectual disabilities in developing and implementing recruitment strategies should also be considered. This has been associated with higher recruitment rates in other studies e.g. (McCarron et al., 2022).

Adaptation and delivery of the CST programme (Spector et al., 2020) required several modifications to enhance its relevance and suitability for adults with Down syndrome (see Tables 3 and 4). Given that participants were younger adults (average age: 30 years), particular attention was needed to ensure the 'reminiscence' component of CST could be meaningfully incorporated into each session. This was achieved by gathering personalised information related to participants' early life experiences (such as childhood holidays, schools attended, and sports played) which proved useful in tailoring content. Engagement and enjoyment were further enhanced by incorporating stimuli that participants had direct familiarity with, including local landmarks, favourite music, and contemporary or personally relevant news items. While this individualised approach effectively increased engagement, it was time-consuming and may present challenges in terms of replication and scalability in studies involving larger cohorts. This would need to be considered carefully for future replication studies. Most of the equipment required to deliver the adapted CST programme (see Table 8) was already available within the service. However, larger-scale implementations may require full procurement of these materials, which should be accounted for during the planning phase. Overall, it took approximately 100 hours to adapt and deliver the 14-session CST programme (approximately 7 hours per session or 17 hours per participant; see Table 7). Future research should further explore the cost-effectiveness and value-for-money of the adapted CST programme, especially in the context of effectiveness and broader implementation, including data manager costs.

The feasibility of the trial design was also supported by positive findings. No concerns were raised regarding the randomisation process by either participants or their proxies, and randomisation did not result in any dropout. All participant outcome measures (modified FULD, subjective wellbeing, and memory self-efficacy) were completed in a single sitting (40-65 minutes) at each timepoint, with good levels of engagement and understanding observed throughout. There were no ceiling or floor effects, and no missing data for these assessments. Similarly, all proxy-reported measures of adaptive behaviour were successfully returned, with follow-up calls ensuring completeness. However, while the assessment process seemed effective, it was also resource- and time-intensive. Planning for a future, larger-scale RCT will need to account for the associated time and costs to ensure assessments can be delivered consistently and without compromising data quality.

Participants in the CST group demonstrated significant improvements in adaptive behaviour compared to the services as usual (SAU) group. These gains were evident both immediately post-intervention (notably in communication and overall adaptive functioning) and at the four-month follow-up (communication, socialisation, and overall adaptive functioning). Episodic memory also improved in the CST group at post-intervention ($p = 0.06$), representing a positive trend that was not observed in the SAU group. These preliminary findings raise the possibility that proactive cognitive stimulation can lead to cognitive gains for adults with Down syndrome. Interestingly, episodic memory outcomes for both groups showed significant gains from post-assessment to follow-up, suggesting a potential practice effect resulting from repeated testing (Calamia et al., 2012). This is particularly noteworthy given the limited existing research on practice effects in individuals with Down syndrome. While shortened versions of the FULD are designed to minimise practice effects (Anderson-Hanley et al., 2013), the observed gains in both groups at follow-up suggest that such effects may still be present in this population and so future research would benefit from targeted efforts to

minimise these further (e.g. develop an additional object set for follow-up on the modified FULD, i.e. Form III). However, we believe that the CST group's improvement in episodic memory from baseline to post-intervention, which was not seen in the SAU group, points toward a possible programme-specific benefit beyond any practice effect.

A key limitation of the present study was the by design small sample size and exploratory nature of the study design, which limit the generalisability of the findings. Another limitation was the inability to blind proxy participants to group allocation, which may have introduced reporting bias in the adaptive behaviour outcomes. Additionally, participants in this study were self-selected, potentially representing a more cognitively able and motivated subgroup of adults with Down syndrome, which may limit the applicability of findings to the wider population. This study focused on adults with Down syndrome and moderate intellectual disability exclusively. It is likely that adults with Down syndrome and mild intellectual disability could also engage with CST, though different adaptations might be needed to suit their abilities. This study excluded adults with severe to profound intellectual disabilities. Future research should aim to develop and test adaptations that make cognitive programmes more accessible to individuals across the full spectrum of intellectual functioning. It will be important to centrally involve adults with intellectual disabilities (experts by experience) in the adaptation of CST in future studies.

Despite its exploratory nature, the current study followed a rigorous, blinded longitudinal randomised controlled trial (RCT) design. A comprehensive set of feasibility indicators was employed to assess the success of the adapted CST programme, and its potential effectiveness was evaluated using outcome variables previously associated with cognitive health in the general population (Wilroth et al., 2023; Mendonca et al., 2022; Beaudoin & Desrichard, 2016). Standardised efficacy measures were used where available (modified FULD, Vineland-3) and were found to be both acceptable and sensitive to change over time.

In cases where appropriate standardised tools were lacking for this population, the research team undertook a multidisciplinary and collaborative adaptation process to develop and adapt self-report measures of subjective wellbeing and memory self-efficacy for use with adults with Down syndrome. This included incorporating direct feedback from adults with moderate intellectual disabilities. The research team plans to evaluate the psychometric properties of these adapted measures to ensure their reliability and validity for future research. To reduce bias, all outcome assessments were conducted by a researcher blinded to group allocation. Furthermore, the CST sessions were delivered by highly experienced and qualified healthcare professionals, all of whom completed a certified CST training day prior to programme delivery.

This study contributes to the emerging evidence base that short-term cognitive programmes (e.g., Cheung, et al., 2022; García-Alba, 2020) can lead to improvements in cognitive functioning for adults with intellectual disabilities. It is hoped that these cognitive gains will in turn support greater independence, enhanced social participation, and increased engagement in cognitively stimulating lifestyle activities helping to build much needed cognitive resilience over the longer term. Given their vulnerability to Alzheimer's disease pathology from a young age, there is a pressing need to evidence base targeted cognitive health programmes for adults with Down syndrome.

The current study has provided valuable data to support the design of a future RCT to test the effectiveness of proactive cognitive stimulation for this cohort. Despite the many challenges faced when conducting full RCTs with individuals with Down syndrome (Mulhall, et al., 2018; Oliver, et al., 2002) there is growing evidence that such studies are possible and significant intervention effects have been found, with sufficient power, in RCTs with 25 individuals with intellectual disabilities per arm (Cooney, et al., 2017) and 50 individuals with intellectual disabilities per arm (Cheung, et al., 2022). Based on our recruitment and attrition rates, a future RCT would require a pool of potential participants of between 305 (for 25 per

arm) and 608 (for 50 per arm) to ensure sufficient power to detect significant gains in episodic memory and adaptive behaviour. This may be best achieved by a large multi-site RCT incorporating multiple intellectual disability service providers.

## Conclusion

To the best of the authors' knowledge, this is the first feasibility randomised controlled trial of an adapted, group-based Cognitive Stimulation Therapy (CST) programme specifically tailored for younger adults with Down syndrome showing no objective signs of memory loss or dementia. Preliminary findings are encouraging, indicating that the programme is both feasible to implement and potentially beneficial for this population. These results support the viability of conducting a larger-scale RCT; however, the development of targeted strategies to enhance participant recruitment will be critical for future research.

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