Cognitive Stimulation Therapy for People with Living with Dementia

An evaluation of facilitators and barriers to intervention delivery in Ireland

Summary Report: Study Findings

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

National College of Ireland

Facilitators and barriers to implementing Cognitive Stimulation Therapy for people with living with dementia in Ireland

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Acknowledgements

First and foremost, we would like to thank the research participants who engaged in interviews and completed surveys for this study. We are extremely grateful to them for generously giving their time to share their thoughts, views, and ideas with us. This project would not have been possible without their input.

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Finally, we would like to thank the Irish Research Council, for providing funding for this study as part of their New Foundations Award Scheme.

Foreword

Research into timely, appropriate, psychosocial interventions for people living with dementia in Ireland is essential. Due to advances in assessment and diagnosis, early identification of dementia is becoming increasingly common. Early diagnosis in turn facilitates an opportunity for early intervention, which we know can have an important positive impact on people's experience of the dementia journey, including improving quality of life and other indicators of well-being and happiness. Although we have seen increased provision of support for people living with dementia and their families in Ireland in recent years, there remains a treatment gap post-diagnosis. People repeatedly report that early diagnosis is not routinely followed by early intervention. We have heard first-hand about people's desire to access timely interventions that can support them to live independently in their communities for longer. When we consider what can be offered, Cognitive Stimulation Therapy (CST) gets a lot of attention due to its evidence base, and because it is consistently recommended by dementia-support guidelines including the World Alzheimer Report, the NICE guidelines, and more recently, the HSE Model of Care. Despite these recommendations and the fact that there are over 400 people in Ireland trained to deliver CST, we don't see CST being routinely offered post-diagnosis. We wanted to find out why this was the case, and how we could move towards greater availability of effective early interventions. We were delighted to receive support from the Irish Research Council's New Foundations Award to work alongside the Alzheimer Society on this project. This report outlines our examination of the barriers and facilitators to CST implementation and provides research-informed recommendations. Caoimhe, Cassy, Eve, and I are so hopeful that this research can translate into a meaningful contribution to the lives of those living with dementia.

Michelle Kelly

Dr Michelle Kelly

Principal Investigator; Associate Professor in Psychology at National College of Ireland

It brings me great pleasure to witness the publication and dissemination of this evaluation of the facilitators and barriers to delivering Cognitive Stimulation Therapy in Ireland. As an organisation committed to empowering and championing the rights of people with dementia and their families to quality supports, The Alzheimer Society of Ireland is proud to have collaborated with the National College of Ireland on this research.

While the dementia landscape is filled with hope and promise of pharmacological approaches, it is vital that we concurrently focus on the implementation of evidence-based psychosocial interventions. By doing so, we can ensure that people living with dementia now, and in the future, can access a greater suite of supports and services. Cognitive Stimulation Therapy is a vital psychosocial support for people affected by dementia, and the benefits are well documented. Notably, the Model of Care for Dementia in Ireland underscores the value of Cognitive Stimulation Therapy and the recommendations of this report enrich our understanding of how implementation can be enhanced.

I sincerely thank Dr Michelle Kelly, Dr Caoimhe Hannigan, Dr Cassandra Dinius, Ms Eve Larkin and all those who generously provided their time and expertise to bring this excellent work to fruition, particularly those who participated in the research. The Alzheimer Society of Ireland is grateful to the Irish Research Council who funded this work through the New Foundations Scheme.

Dr Laura O'Philbin

Research & Policy Manager at the Alzheimer Society of Ireland

1. Background

What is Cognitive Stimulation Therapy?

Cognitive Stimulation Therapy (CST) is an evidence-based intervention for people with mild-to-moderate dementia. CST is a group-based intervention, where people living with dementia come together to work with a trained facilitator, engaging in different activities to trigger thinking and concentration. The intervention is usually run by healthcare professionals or dementia specialists, with sessions taking place over 7-14 weeks. Each session focuses on a different theme like creativity or current affairs. CST is well suited to people who want to be involved in activities that are good for their brain, and allows people to meet others with similar experiences to themselves.

What can Cognitive Stimulation Therapy do?

Studies show that CST can improve cognitive function, communication, and thinking skills. In interviews with people living with dementia across Ireland and the UK, people have reported improvements in how they feel about their memory, their confidence, and how engaged they are after completing CST.

CST has been recommended in international guidelines for best practice in the treatment of dementia, including the National Institute for Health and Care Excellence (NICE) guidelines in the UK and the World Alzheimer Report. In Ireland, the new HSE Model of Care for Dementia, published in 2023, recommended that CST should be made available to people diagnosed with dementia.

Is Cognitive Stimulation Therapy available in Ireland?

We estimate that there are about 400 people in Ireland who have been trained to deliver CST, but CST is still not routinely available here. In comparison, CST is provided as standard in at least 85 memory clinics in the UK.

Aims of this project

The primary aim of this project was to understand why CST is not widely available in Ireland, despite many professionals being trained to deliver this service—to identify the ‘barriers’ to providing CST at present. We also wanted to identify what factors might help to make CST more widely available in Ireland going forward—factors that we called ‘facilitators’ for increasing delivery of CST.

2. Methodology: What we did

Who did this research?

The ProBrain Lab at National College of Ireland worked with The Alzheimer Society of Ireland to design and carry out this research project. The project was led by Dr Michelle Kelly, Co-Director of the ProBrain Lab. We received funding from the Irish Research Council to conduct the study.

Who took part in the research?

- Our researchers sent an online survey to healthcare professionals and dementia specialists who have been trained to deliver CST.
- We conducted interviews with key stakeholders including people living with dementia, their family members or caregivers, healthcare professionals, and policy professionals.

What information did we collect?

Survey with people trained to deliver CST (62 Responses)	• Online survey sent to those who had completed a CST training course. • Questions included whether they had delivered CST groups following their training, and why/why not. We aimed to identify what had helped people to run groups, and what had prevented people from offering CST.
Interviews with people living with dementia and their family members (10 responses)	• Interviews with 5 people living with dementia, and 5 family members (10 people in total). • People living with dementia and family members gave their opinions about interventions like CST, willingness to attend CST, and what would facilitate them to access supports like this. • Questions also explored barriers for engaging in CST and possible solutions.
Interviews with healthcare providers and policy professionals (10 responses)	• Interviews with policy professionals, doctors, and other healthcare professionals who work in dementia services (10 in total). • Questions included knowledge about CST, opinions about interventions like CST, and explored their views about the key barriers and facilitators to making CST more widely available in Ireland.

4. Survey Findings: People trained in CST

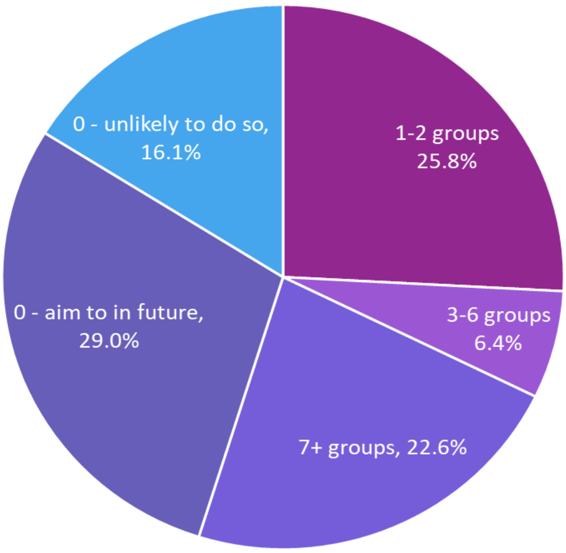
Profile of respondents

- 57 females (91.9%), 4 males (6.5%) and 1 person with another gender identity (1.6%)
- Most respondents were dementia advisors/dementia specialists (43.5%) or Speech and Language/Occupational Therapists (24.2%)
- Other occupations included care assistants/home care coordinators, psychologists, and nurses.
- Respondents mostly worked with people living with dementia on a daily or weekly basis (67.7%) or with carers/families (24.2%)

Experience with CST

- Almost all (91.9%) respondents attended CST training in Ireland, that was delivered by an accredited trainer.
- **Just over half (54.8%) had run CST groups** following their training.
- Among those who had delivered CST, the extent of delivery varied—only 14 participants (22.6%) had led more than 7 groups; and **among those who had run groups, about half (48.5%) had delivered CST to less than 10 people.**

Delivery of CST Groups



Barriers and Facilitators

At the end of the survey we asked participants to write a short note explaining the key barriers and facilitators to making CST more widely available. They wrote about:

Resources: time (for preparation and to run); suitable venue and location; sufficient staff and managerial support; coordinated standard delivery; access to materials; funding

Education: awareness of CST for public, families, professionals; understanding of benefits; training; management input/buy-in.

Logistics: transport; participant recruitment; administrative support; accessibility.

Attitudes to CST

- Most participants **agreed or strongly agreed** that CST was an **acceptable and effective** intervention.
- Most participants **agreed or strongly agreed** that CST was likely to **improve patient care and/or the lives of those with dementia**.
- The more effective people thought CST was, the more likely they were to run CST groups.
- People were more likely to run a greater number of CST groups when they saw the benefits first hand.

5. Interview Findings: People living with dementia and their families

Profile of Participants

- Ten people impacted by dementia, including five people diagnosed with dementia and five family members who provided support and/or care to a loved one with dementia.
- Participants with dementia were aged between 51-89 years (40% female).
- Family members or carers were aged between 33-59 years (80% female).
- Different types of dementia were represented including Alzheimer's disease, younger onset Alzheimer's, posterior cortical atrophy, and vascular dementia. Average age at diagnosis was 68.8 years (range 50-83 years).
- More people lived in urban (60%) than rural (40%) settings.

Knowledge and Awareness

Most of the people we interviewed hadn't heard about CST and didn't know much about it.

> *"I think like myself, people are not aware of what's available. I mean, I definitely wasn't aware of what was available and I'm in a state of mind where I wouldn't even know where to look."*

Participants were not aware that interventions like CST could have a positive impact on their memory, cognition, or symptoms.

> *"We were told there's nothing that could help your situation, they say these things like the choir and stuff to keep you interested in activities. But they didn't say that that can help you with your symptoms."*

A lack of knowledge about the intervention and its potential benefits was a key barrier to implementation—participants were not engaging with CST because they did not know about it.

Beyond knowing that CST is available, participants reported wanting information about the quality and efficacy of the intervention to inform their decision about whether to engage with it.

> *"It would have to be high quality. If it wasn't, you know, properly delivered and managed, I wouldn't see it. My expectation is that it would be well delivered...how would you know that I was as good as it needs to be so that it's effective?"*

Importance of Post-Diagnostic Supports

Participants frequently discussed negative emotions about the diagnostic process, with insufficient post-diagnostic support as a common theme.

> *"It was like we were just left to the wind, you know, and you do nothing."*

Participants reported wanting to be able to access a greater level of supports and interventions like CST after their diagnosis. Participants felt it was important that an evidence-based intervention like CST was available, and that this is something they should be told about at diagnosis.

> *"Not great support from the consultants when we got the diagnosis, we didn't really know where to go next or what to do. And then Dad's GP was no help either, he didn't really offer any*

> *support or advice."*

Particular challenges were noted in accessing supports for those diagnosed with younger-onset dementia.

> *"I've no other support in the community or anything. I tried a few places, but they say I'm too young. You have to be 65 or over."*

Acceptability of CST

Participants spoke about the importance of interventions or activities being compatible with their interests—this was considered a potential facilitator for implementing CST, since most participants expressed positive views about the activities involved and the social aspect of the group-based intervention. Family members said interventions like CST provided an opportunity for their loved ones to engage in activities that were independent from the rest of the family, and kept them interested in attending events outside of the home.

> *"Just so that you're not sitting around the house, day after day, after day...it's great to have something...where you're getting out. You prepare yourself, you go out, you do the activity. You are like this, this is an activity that is stimulating."*
>
> *"It's the activities really and doing things with like-minded people."*

Participants also liked that the intervention would provide an opportunity to interact with others in similar situations to themselves. Some reported feelings of loneliness and isolation following their diagnosis, and felt CST could help to alleviate these concerns.

> *"Honestly, I think the main attraction is that I would be with people who understand because we're probably in a similar situation. It'd be comforting and I would definitely be more relaxed in that sort of situation."*

Those with younger-onset dementia wanted to make sure they would be eligible to participate in CST, and were happy to know that this was an intervention that is suitable for all age groups.

Further to the earlier point about availability of services for younger-onset cases, participants also discussed age-appropriateness of interventions in terms of personal compatibility—some younger participants expressed hesitancy around participating in an intervention that may be catered towards specific interests of older people.

> *"I find it really hard to place myself in that cohort of people."*

For some participants, the negative impact their diagnosis had on their mental health was considered a barrier to engaging with CST.

> *"And if you said to me, you know, let's go and do that stuff now—where I am right now, I probably would find it difficult to take on at this point...that's probably more about my frame of mind more than anything else...it would be difficult for me to get outside my current space to do it."*

Resources and Practical Considerations

Issues related to access and transport were considered potential barriers to engaging with CST, particularly for participants living in rural areas. Having the intervention available locally would make it easier to attend. The time involved in travelling to and from the intervention was an important consideration, particularly in relation to carer burden, where participants were reliant on family members for transport.

> *"If it's somewhere nearby that it's not too much of trek, too much of an ordeal."*
>
> *"Location. The journey...I think sometimes if it's too long, I just get very tired. Because I'm caring and supporting and that's wear and tear on your own memory."*

Most people learn about dementia from their doctors or community services, so these would be good places to provide information about CST.

6. Interview Findings: Policy makers and healthcare professionals

Profile of Participants

- Participants were female (60%) and male (40%) experts working in dementia services or dementia-related policy roles in Ireland
- Healthcare professionals (n=5) worked in various roles within the HSE and were each directly involved in providing care for people living with dementia.
- Policy professionals worked at a high level (managers, directors, CEOs) in government organisations (n=2) and NGO/charity/advocacy organisations (n=3)

Knowledge, Awareness, and Information

Some of the professionals we interviewed were very familiar with CST as an intervention, but others said they had little or no knowledge about it. A lack of knowledge about CST among many key stakeholders was considered a barrier to implementation.

> *"I would say most people probably don't know what cognitive stimulation therapy is."*

A lack of information about CST, and of a unified, coordinated approach was another barrier—this can cause inconsistency for the kinds of services available to people living with dementia.

> *"If somebody was looking for a local service and they google it, there's no one organisation who's leading it. So you have bits and pieces….nobody's taking responsibility to be a provider in that space."*

Increasing knowledge about CST was considered important, because participants said that demand from the public is an important facilitator to drive support for these types of interventions:

> *"You also need people on the ground to be asking for it. That's really powerful in terms of advocacy."*
> *"...people aren't knocking down the door looking for CST, so you have to kind of establish that there is a need for it."*

Several participants said the scientific evidence-base available for CST is an important factor for encouraging healthcare professionals and policy makers to implement it. Some noted that they would like to see further evidence on longer term impacts of the intervention.

> *"Any time I've tried to explain CST to people, I'll always refer to the evidence base. It seems like there's people who think it's just...some kind of distraction therapy...It's actually, you know, it's researched. It has an evidence base behind it. We're not just here providing it for the sake of it."*
> *"The policymakers will listen to evidence. So that's really important, research and evidence."*

Resources and Funding

A lack of sufficient resources for dementia services was recognised as a key barrier to implementation of interventions like CST.

> *"There's still a huge amount to do in relation to service provision".*

Some participants also highlighted a lack of consistency in services due to the distribution of resources leading to a "postcode lottery" in terms of services that people living with dementia can access.

In terms of availability of resources, key challenges identified included a lack of available staff, or when staff were available, a lack of time or a specific remit to deliver CST as part of their role.

> *"there's a huge supply issue of qualified staff across the healthcare system...so while there is money there, it's difficult to find qualified people to fill the roles."*

> *"I think when it becomes an add-on to an already really busy role and the person is overworked, then it becomes really difficult."*

Participants also highlighted other resources that need to be in place to support delivery of an intervention like CST—these included having access to a suitable space, funding for materials, and administrative support.

The new HSE Model of Care for Dementia was seen as important policy development, bringing increased funding and resources that could help to make CST more widely available.

Culture and Attitudes

Organisational culture and attitudes among leaders within the healthcare system were identified as an important influence on whether CST is available. A number of participants discussed the need for "buy in" from management –beyond agreeing to provide the intervention, support is required for the resources, space, and time required for delivery:

> *"There's a lot of people would say, do the CST training, think it's amazing, they're like 'I'm going to go and implement it' but all of a sudden their workload grows too much, whereas they really need is their manager to say no, we need to prioritise this, let's take some of that workload off so you could prioritise CST."*

As well as the broader organisational culture, the attitudes of individual healthcare professionals towards CST, and towards non-pharmacological interventions for dementia more generally, were also considered important. The healthcare professionals we spoke to demonstrated a holistic and person-centred approach to care for people living with dementia, and this was reflected in a motivation to provide interventions like CST to benefit the overall quality of life of patients and their families.

> *"I suppose people's understanding of what the benefits of it will be. I think that will be, that's really important. That's ultimately what will impact on people delivering this and they will want to make sure it's offering something to the person—it's making a difference."*

While participants generally reported a positive attitude to interventions like CST, they also acknowledged that other services or interventions might be prioritised in the context of limited resources.

> *"I feel like in dementia care, everyone is fire fighting all of the time and there's so many, I'd say of the people we work with are not necessarily in crisis but they're, you know, they're urgently in need of other types of supports and services that I guess are more immediate that there is no time for kind of luxuries like CST."*

Participants also discussed the idea of relative priorities in terms of assessment and diagnosis, newly available pharmacological treatments, and developments in diagnostic technologies—noting a potential barrier associated with healthcare professionals needing to decide where to invest the limited time they have available.

7. Key Findings and Conclusions

This research aimed to understand why CST is not widely available in Ireland, despite many healthcare professionals and dementia specialists being trained to deliver this intervention. We also aimed to identify ways to increase the availability of CST in future.

The study found that in general there is strong support for CST, and many people are interested in this evidence-based intervention. Below are some key findings and conclusions from each part of the study:

1. Survey of Trained Practitioners

While there has been good uptake of training in CST (training records indicate approximately 400 people have completed the accredited training course in Ireland), this does not seem to be translating to widespread implementation:

- Almost half of the trained practitioners who responded to our survey had not run any CST intervention following their training.
- Furthermore, even among those who had run CST groups, the extent of delivery was relatively low, with most participants having run only a small number of groups and having delivered CST to relatively low numbers of people living with dementia.

While a large proportion of the surveyed trained practitioners had not delivered CST, overall, they reported very positive attitudes towards the intervention and felt that it was effective in improving patient care and/or the lives of those with dementia. Most participants reported wanting to provide CST more often. More positive attitudes towards the intervention were significantly associated with likelihood of having run CST groups, and with the number of CST groups delivered.

The qualitative survey data suggest that the key barriers to intervention delivery are practical – mainly related to availability of resources and logistics, rather than being due to an unwillingness to deliver CST or a perception that it is not acceptable or effective. Information and awareness of the intervention were also considered important factors to address going forward.

2. Interviews with People Living with Dementia and their Families

There is a huge demand for post-diagnostic supports and services among those impacted by dementia. Many participants reported difficulties in accessing information about interventions or services and had not heard of or did not know much about CST. Participants would like to receive information about interventions like CST, including where they can be accessed but also about the evidence for the quality and efficacy. Healthcare professionals and community services were trusted and commonly accessed sources of information, and so would be well placed to deliver this information.

Participants reported positive views about CST when it was described to them, particularly in terms of the activities involved and the social aspect of the group-based intervention. When making an intervention like CST available, particular consideration should be given to those with young-onset presentations, to ensure that age-limits do not pose a barrier to accessing the service and to perhaps tailor the intervention to include activities that are appropriate and acceptable for this age group. Practical considerations are also important, particularly around providing the intervention locally and in an accessible space.

3. Interviews with Healthcare and Policy Professionals

Policy makers and healthcare professionals have mixed knowledge about CST and the evidence base behind it. Participants said there is a need for clear and accessible information about the intervention to encourage implementation. At present, a lack of a cohesive strategy or unified approach is a barrier to making CST available across the country. Scientific evidence was considered a key facilitator for encouraging policy makers and healthcare professionals to implement CST – some participants felt there was strong evidence to support implementation, and others would like to see more extensive evidence, particularly related to longer-term impacts of the intervention.

Public awareness was considered another important factor—when the public knows about services like CST and asks for them, this motivates policy makers to provide support and investment to deliver the service. We need more people to advocate for the intervention to encourage wider availability.

Additional resources are required if CST is to be made widely available within memory services in Ireland – participants noted challenges related to availability of staff, time, space, administrative support, and funding. The new HSE Model of Care for Dementia was recognised as a positive development that may help to address some of these resourcing issues.

A supportive culture, where management recognises the value of interventions like CST and provides necessary resources, is essential for increasing implementation. The value of CST, and evidence of benefits for people living with dementia, needs to be clear if it is to be prioritised in a service provision landscape where resources are often limited.

Key Messages

- People living with dementia and their families, those trained to deliver CST, and other health and social care professionals are supportive of CST and are interested in it. The most important aspect of CST is evidence of benefits for people living with dementia.
- Awareness and knowledge of CST is considered to be very limited, among the general public, but also among people living with dementia, their families, and professionals working in dementia services and care. Increasing awareness of CST, and providing more clearly accessible information about the intervention, is important.
- A lack of resources - including staff, time, space, and funding - is considered a key barrier to making CST more widely available.

7. Recommendations

1. **Awareness and Information:** There are currently low levels of awareness about CST and its benefits among the public, people impacted by dementia, healthcare professionals, and policy makers. Awareness-raising activities can increase demand for the intervention, drive advocacy for making it available, and encourage implementation. There is a need for clear, consistent, and accessible information about CST as an early intervention for mild-to-moderate dementia; and as an intervention that is suitable for those with younger onset dementia. There should be a central online location where information about CST is available and updated regularly (e.g., the Understand Together website); print materials could be developed for use by community-based services, healthcare professionals in clinical settings, and/or for signposting to where CST is being offered; and information about CST could be shared via public seminars, Dementia Cafe's and Dementia Advisors.
2. **Staffing and Resources:** Where services are interested in offering CST, staff should either be recruited with a designated role to deliver post-diagnostic interventions like CST, or delivery of CST needs to be recognised as a specific part of existing staff roles and workload, with sufficient time allocated for intervention delivery. In addition to staff, resources should include administrative support for recruitment and participant engagement, an appropriate space to deliver CST, and funding for materials and equipment. Establishing a Community of Practice where trained practitioners can share learnings and experiences could also support increased delivery of CST nationwide.
3. **Training**: While there is good uptake of training in CST, it is unclear if this training is reaching those most likely to implement the intervention—16% of those surveyed had completed training but did not foresee themselves implementing CST as part of their current role. Ensuring that training is targeted towards those who are best placed to deliver CST may help to increase implementation. Having managers set targets for intervention delivery following their staff completing training may also help to increase the likelihood that training translates into implementation.
4. **Coordination and Ownership:** A coordinated, unified approach to delivering CST, with perhaps one organisation leading on service delivery would be very beneficial. This could include having a central location/website to list where CST is available throughout the country. The introduction of the HSE Model of Care provides important opportunities for increasing implementation of CST—and new MASS and RSMC structures may be well-suited to delivering the intervention. Where other services are running CST, communication across services and disciplines, as well as a coordinated approach to ensuring equitable access would be highly preferred.
5. **Research:** The evidence-base for interventions is crucial in encouraging policy makers and healthcare professionals to implement these supports. Further research is needed to evaluate the effectiveness of CST in an Irish context, particularly in terms of longer-term impacts. Where increased post-diagnostic supports (including CST) are made available through pathways identified within the HSE Model of Care, scientific evaluation of the effectiveness of intervention implementation should be prioritised.

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