

**Evaluation of the Rights Made Real training
course for people living with dementia**



THE Alzheimer
SOCIETY OF IRELAND



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1. Background and Context

The Alzheimer Society of Ireland (ASI) is the leading dementia-specific service provider in Ireland. As a national non-profit organisation, The ASI advocates, empowers and champions the rights of people living with dementia and their communities to quality support and services.

The ASI provides numerous award-winning training programmes both online and in person for family carers and those indirectly involved in the care of a loved one who is living with dementia.

The Irish Dementia Working Group

The Irish Dementia Working Group (IDWG) was set up in 2013 and is an advocacy group of people living with dementia. It is supported by The ASI, and their work is overseen by a Steering Group comprised of people living with dementia. The group is an independent campaigning voice for the lived experience of dementia, with members living in all parts of Ireland.

Human Rights Charter

In April 2016, The Alzheimer Society of Ireland and the Irish Dementia Working Group published a charter highlighting the rights of people with dementia. The Charter of Rights for People with Dementia calls for greater participation, accountability, equality, empowerment, and legal recognition of the rights of people with dementia. The charter was launched by former President of Ireland Mary Robinson, who noted:

“I hope that the launch of this charter will enable us all to see people with dementia in a new light, with the same human rights as all of us and with a voice that needs to be heard. It was a significant step to see the importance of using a human rights lens because that would empower those with dementia to be as involved as possible in addressing the challenges. That is what has happened, and that is what this Charter is all about.”

Human Rights Facilitator

The external Human Rights facilitator was a solicitor who has practised in the area of human rights and equality law for a number of years. She has acted as a mediator and has worked in personal advocacy for people living with dementia. She also has a certificate in conflict resolution and facilitation.

The rationale for training

The ASI's mission and vision is for an Ireland where people on the journey of dementia are valued and supported. We advocate, empower and champion the rights of people living with dementia and their families.

“People living with dementia can be denied their human rights from the time of diagnosis. We are not always respected or informed. As we live with the disease, we navigate systems and structures which are not person-centred or rights-based. As a result, either deliberately or by omission, our human rights are denied.”

Dr. Helen Rochford Brennan, member of The Irish Dementia Working Group, Alzheimer Europe Conference, October 2018

The Irish Dementia Working Group believed the next step in promoting human rights amongst people living with dementia was to empower those living with dementia to make those rights real and applicable in their everyday lives. Human rights as a topic can seem quite intangible, academic, and sitting in books and journals. To build on previous work and empower people with dementia to know about the importance of their human rights, The ASI sought funding from the Irish Human Rights and Equality Commission, which was successful in providing the first training to people living with dementia on the topic of human rights.

Following a successful application to the Irish Human Rights and Equality Commission, The Irish Dementia Working Group commissioned Prof Suzanne Cahill to collaborate with the group to develop training for people living with dementia to learn more about their human rights. This was delivered and adapted by an external facilitator, known as the “Rights Made Real” training course.

Aims of Rights Made Real Training

The purpose of the Rights Made Real training is:

- To empower people living with dementia to understand what their human rights are and to make those rights real and applicable in their lives.
- To move human rights from something intangible that exists on paper to something that can impact the lives of people with dementia in a positive manner.

2. Methodology

The impact of the Rights Made Real training for people living with dementia was assessed using online and face-to-face surveys. The Advocacy, Engagement and Participation (AEP) Officer with the Irish Dementia Working Group and the external Human Rights Facilitator were interviewed to share their thoughts and experiences. Data was collected by two members of the Research team, who were not involved in the course in any other way.

Data collection with course participants

- Pre and post-training surveys were completed with participants on the first and last day of training sessions. Pre-training surveys served as a baseline for thoughts and perceptions, and follow-up post-training surveys allowed us to investigate the impact of the training on level of knowledge and understanding of human rights.
- Surveys were completed on both sites, Cork and Dublin. Participants were given the option to either complete the survey online or in-person with a member of staff.
- Both surveys contained a mix of open-ended questions and Likert scale questions.
- All survey data were anonymous, with no health information or direct personal information collected.

It was also important to understand the day-to-day workings and organisation of the training, the first of its kind specifically designed for people living with dementia. To evaluate this component, we undertook two semi-structured interviews (with the external Human Rights Facilitator and the IDWG AEP Officer, respectively), each lasting approximately one hour.

Report Structure

The findings of this evaluation are divided into two sections. The first section encompasses the quantitative data from participants of the course, with the second section focusing on the qualitative data from interviews undertaken with the Human Rights Course Facilitator and the IDWG AEP Officer.

3. Section 1: Survey Data

Profile of Participants

Surveys were collected from September until October 2022; A total of 14 participants completed the pre-training survey and 15 participants completed the post-training survey. The online interviews were conducted in October 2022 over the course of one hour.

Data collection with Facilitators and organisers

- A semi-structured Zoom interview was conducted with the facilitator of the training to gain her insights of the course via Zoom
- A semi-structured Zoom interview was also conducted with the IDWG Advocacy, Engagement and Participation Officer to understand the inner workings and organisation of the training course.

Data was collected from September until October; A total of 14 participants completed the pre-training survey and 15 participants completed the post-training survey. Online interviews were conducted in October 2022 over the course of one hour.

Pre-training surveys served as a baseline for thoughts and perceptions, and follow-up post-training surveys allowed us to investigate the impact of the training on level of knowledge and understanding of human rights.

Pre-training participant demographics

Participants	Venue	Men	Women
1st training session	Cork	3	4
1st training session	Dublin	3	4

Participants had different types of dementia, including frontotemporal dementia, Lewy Body Dementia and Alzheimer's Disease. Eleven participants were already members of the Irish Dementia Working Group, whilst six participants were non-members who were interested in taking part in training.

Cork

- 4 participants completed the survey online prior to attending the first day of training
- 3 participants completed the survey in person with a member of staff

Participants who opted to complete the survey in person did so in conjunction with an ASI staff member prior to the beginning of the training.

Dublin

All participants completed the survey in person with a member of staff. One survey was completed prior to the event starting, and the others were completed during lunch break.

All participants in both cohorts found the signup process either 'Easy' or 'Very Easy' (100%)

Post-training participant demographics

Participants	Venue	Men	Women
2nd training session	Cork	2	4
2nd training session	Dublin	5	4

Key Areas

A) *Understanding and perception of training*

When asked to describe their level of understanding of human rights before starting the course:

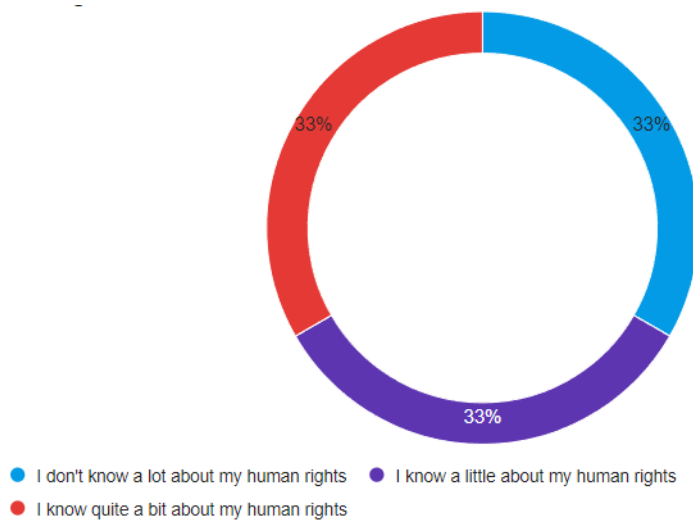


Figure A. Levels of understanding of human rights before starting the course

When compared by region, participants who attended in Cork were more likely to report that they didn't know a lot about their human rights before beginning the course (n=4) compared to participants attending in Dublin (n=0).

75% of participants were unaware of the Charter for Human Rights for People with Dementia before undertaking the course.

When asked about what they are hoping to learn or take away from the course, open-ended answers included *'learning more about my human rights'* (n=8), *'building awareness'*, *'learning from others perspectives'* and *'making a contribution'*.

In the post-training survey completed after the final session, we again asked participants to rate their understanding of their own human rights following this course. The majority of participants in Dublin (n=5, 62.5%) stated that they now knew *'Quite a bit about my human rights'*. Overall, 67% knew *'Quite a bit about my human rights'* and 33% stated they knew *'A little about my human rights'*.

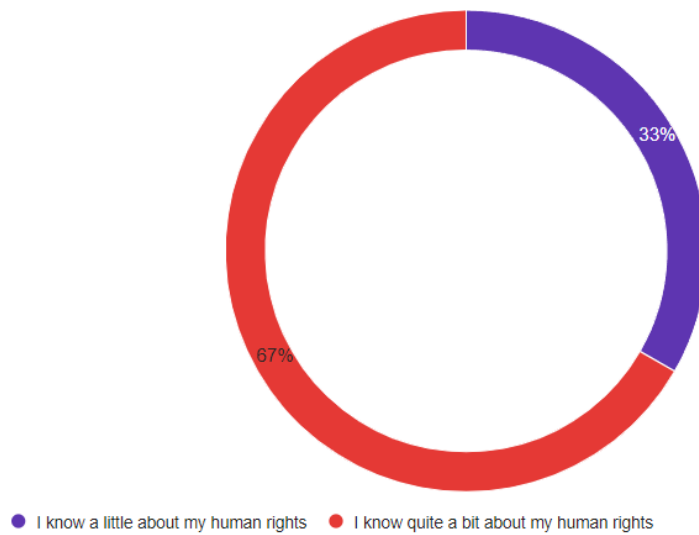


Figure B. Levels of understanding of human rights after completing the course

B) Training course & empowerment

Following completion of the course, participants were asked if they had learned about how their human rights could be upheld with 83% saying ‘*Definitely Yes*’, and 17% saying ‘*Probably Yes*’. When asked if they knew how to act if their human rights were not upheld;



Figure C. “If your human rights are not upheld, do you know how to act on this?”

The majority of participants said ‘*Yes*’ (77%) and 15% answered ‘*Maybe*’. Only 8% (n=1) said ‘*No*’.

Following completion of the training, participants were asked to rate how empowered they felt to make human rights real and applicable in their lives. The majority (92%) felt ‘*Very Empowered*’ and 8% felt ‘*A little bit empowered*’.

Many of the participants had different thoughts and opinions on what they were going to take away from the course, which included;

“My rights are as equal as anyone else’s. I’m entitled like everyone else”

“Definitely feeling more confident”

“I know how to stand up for my rights. I’m going to look over notes and learn more”

“Being able to help new people, talk about the work of ASI and work of IDWG”

Overall, participants reported that they really enjoyed the course, the social aspects of it as well as the information given to them as part of the training. It offered them a sounding board and a safe environment with their peers and others in similar situations.

C) Feelings & Emotions

Participants' emotions prior to taking part in the course; many said they were looking forward to the course, while others reported feeling a little apprehensive and nervous. This apprehension was attributed to not being used to face-to-face meetings after the COVID-19 pandemic and uncertainty around the course content, and getting lost. One participant stated:

“I haven’t seen something like this at all. Worried I won’t remember it in two days. When I go home, it will be out of my brain.”

Others looked forward to meeting in person, with the online environment not appealing to them. There was a general feeling that in-person meetings were preferential as it not only allowed participants to be able to see other face to face but also gave them the opportunity to socialise. One participant noted:

“Hopes for the day - to have the craic!”

Those who attended in Dublin (n=5) reported looking forward to the course more than those in Cork (n=3). When asked about what they were looking forward to most, this differed slightly across venues.

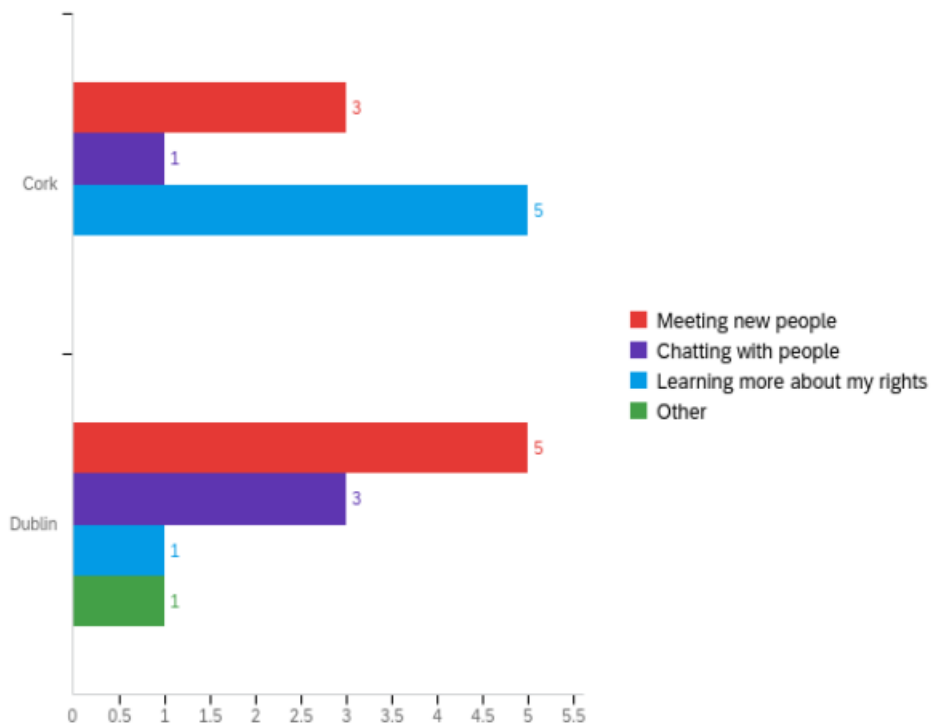


Figure D. Participants' responses to "What are you most looking forward to?"

The majority of participants (42%) were looking forward to meeting new people and engaging with their peers. When asked how helpful they thought the course would be for them, 58% said 'Very Helpful' and 42% said 'Helpful'. When broken down by training venue, those who attended in Cork were more looking forward to learning about their rights (83%), compared to their counterparts in Dublin who were looking forward to meeting new people most (62.5%).

Upon completing the training, we asked participants how they felt. All participants reported feeling positive about having completed the course, "armed with information" and empowered to speak up for themselves and for others.

D) Challenges faced throughout the training

When asked about any challenges that you might have come across during the course, whether it be from content, type and style of delivery, or keeping up with information, the majority of participants reported that they did not come across many challenges. One participant found it hard to communicate with others due to his

dementia, which he mentioned as a challenge, and another person reported finding it hard to keep up with the information due to having to take notes. This could be alleviated by a support person in place or having notes taken and given to participants at the end of the day. The Human Rights facilitator did have 'I want to speak' cards available, and their use was explained to participants. Participants may have chosen not to utilise these cards, but for future training, these could be further explained or utilised. Another participant mentioned that she would have preferred to have had a later morning start, around 11 a.m. as she had to travel to get to the venue.

E) *Feedback and areas for improvement*

Overall, participants left feeling positive, having enjoyed the learning component and the social aspect of the training.

Participants' overall impressions of the course were positive;

- Many liked the small group format of the course with the content allowing them to put themselves in the situations posed.
- The majority found the Human Rights facilitator to be well-organised and good at explaining things.
- The majority of participants also felt that they had received '*Just the right amount of information*' (92%), with just one person (8%) stating they did not get enough information as part of the course.
- All participants (100%) preferred the in-person setting, however, two participants were open to hybrid working and training.

There were a number of areas that participants suggested for improvement. One participant mentioned that the use of music could be helpful, just to get people in the mood and could be soothing. Another suggestion was perhaps to have a brief introduction amongst everyone just to know everyone's background. One person also suggested that the course should be run in the morning, as they felt the day was a little long running until late afternoon. Another person also suggested that more case studies be utilised for future training.

A really important suggestion noted by a number of participants was the use of recordings/technology to supplement the training. This would help participants not to miss anything taking notes and would allow playback at a later stage.

Limitations

We identified two limitations to this evaluation. Firstly, data collected as part of the pre-training course completed in-person in Dublin was done during lunch due to unexpected staff shortages while data in Cork was collected in the morning before the session. At this point, participants in Dublin would have undertaken some training, potentially impacting responses to training questions. Some responses related to questions around thoughts and opinions prior to taking part in the course will differ in comparison to the cohort in Cork who were not exposed to any training before completing the pre-training survey.

Secondly, there were a number of participants in Cork and Dublin who could only attend part of the training; therefore, their data was not collected or only partially collected. Attrition in completion of the programme was not significant however, we identified this as a limitation to this work. It is important to remember here that participants have a diagnosis of dementia, and with that, an acknowledgement that attrition within this cohort is expected.

Summary of Key Points

- Prior to starting the course, participants had a varied knowledge of their own human rights, with almost a third having no knowledge. Following completion of the course, the majority of participants (62.5%) said they knew quite a bit.
- 83% agreed that they had learnt about how their own human rights could be upheld, and 77% stated that if they felt their human rights were not being upheld they knew how to act in that situation.
- 92% felt that following completion of this course, they felt very empowered to make human rights real and applicable in their lives.
- There were mixed feelings prior to starting the course, including some anxiety but also optimism, but upon conclusion, all of the participants overwhelmingly noted feeling positive about having completed the training and armed with the knowledge that was given to them.
- Challenges faced included duration of the day, trouble communicating and taking notes.
- Suggestions for improvement included the use of technology to record the training sessions so that participants could stay present in sessions, knowing a recording would be made available later. Others included improved introductions during the small sessions and the use of music to ease the groups together.

4. Section 2: Interview Data

Data from interviews with the Human Rights facilitator(HRF) and IDWG AEP Officer were pooled and grouped into broad themes.

A) *Group composition and experience*

There had been an initial plan to include a person living with dementia as a formal co-facilitator as part of each session. The person identified was ill, so this wasn't possible. However, there were some experienced members of the IDWG in sessions who acted as informal co-facilitators and, in particular, shared their experiences.

On her thoughts about the co-facilitation, the IDWG AEP Officer also made note of the importance of having an experienced member of the IDWG in place:

"I think that made a huge difference to people's comfort levels...Yeah, I definitely think it just helped relax the room because the nerves, and I suppose that's something I didn't anticipate. The nerves were very high" (IDWG AEP)

This was also identified by the Human Rights facilitator. Both felt that having a formal co-facilitator, would have improved people's ability to connect as a group and help them settle in the group.

*"One group gelled quicker and had a warmer feel possible due to the presence of *Person A from the IDWG and subsequently *Person B. The other group was also great but had a different mix of personalities and types of dementia, a slightly edgier feel and less consistent attendance, including one day where there 9 people, and it was definitely a bit too many. There was also no obvious "co-facilitator"...which I think made a significant difference"(HRF)*

It was also a challenge to manage louder voices and quieter voices in the group dynamic, ensuring that everyone had equal opportunity to speak and contribute their perspectives.

"So, I suppose, and that's tricky with this group, because, uh, you know, in a different group you might be a bit more dogmatic about creating a space and asking the quieter people to speak up. But you don't want to put anybody on the spot, either. So, um, so that can lean towards letting the people who are more comfortable about speaking dominated by. It's a hard one to balance because the last thing you want to do is put somebody under

pressure.” (HRF)

There were also some challenges for the Human Rights facilitator as there were one or two people who struggled to communicate due to language difficulties.

*“I could never ask (*Person C) direct, a direct question about anything. I could never really approach directly about anything. I might try to keep lots of eye contact and to make jokes, and to them in that, you know, and put them on the spot directly...(they) would lose (their) language automatically if you directed something at (them). And so all was going to be difficult to judge how to best associate somebody like that with their experience in the class.” (HRF)*

Group size varied across sessions, with some participants being able to attend all, and others only able to attend one or two sessions. Where group sizes were larger, small group discussions could have been utilised, particularly for people who were new to the IDWG or non-members.

“ Maybe smaller group work throughout the course would work well. In any situation, there are always people who are more confident and don’t hesitate to speak out. I feel in smaller groups all participants may feel confident to speak too” (IDWG AEP)

B) Course material

The Human Rights Facilitator based her facilitated sessions on the course content developed externally but she had to adopt an agile approach to respond to the unique needs of people with dementia as learners. The facilitator mentioned that while the course was written by someone else, she was given a level of freedom and trust to work with the course material and deliver it in her own way.

“It felt a little bit academic... My approach was also to try to angle it directly towards lived experience, you know”. (HRF)

When asked about her feelings prior to facilitating the session, the trainer noted that she was a little apprehensive about delivering content that she didn’t directly design, however, she had a wealth of experience in working with people with dementia and the skills to ‘read the room’, feeling confident to tailor the sessions where needed. The Human Rights Facilitator also felt that she had to pivot to present some of the material more directly to participants with the lived experience of dementia. Both she and the IDWG AEP Officer noted that video content and story vignettes were thoroughly enjoyed by participants.

Whilst participants were provided with a certain level of content, the IDWG facilitator was unsure to what extent participants retained the formal knowledge. This, however, was very much offset by how participants felt.

“I don't know... how much information itself was retained. But I do know people felt very empowered...People felt listened to, respected...For some people, it is the first time they've been in that setting with peers and the same situation, and I think that was hugely beneficial for them” (IDWG AEP)

“One of the participants that went to it wasn't able to tell their partner what had happened, or what the course content was, but was in tip-top form and (their partner) said this is the best form I've seen him in, in so long. So, even though he might not retain the information, he certainly retained that feeling he got, and knowing that his rights were being listened to” (IDWG AEP)

One of the suggestions for improvement or change mirrored in participants' feedback was that of having printed or recorded material available for participants at the end of each day. This could help with retention and provide some material to bring home and discuss with family members/spouses.

“A one-page summary of each module should be provided. I think there were concerns as to whether the “I have Dementia -I have Rights” booklet might be too complex, but it was written for precisely this audience, was plain-English and won a Crystal Clear award, and we covered more or less all of the material in it in class with the participants having no difficulty in engaging, just in retention. I personally feel it would be a nice thing for participants to have to keep” (HRF)

“People didn't remember two weeks previous what information had been covered. I certainly think people should be leaving probably every day with something in their hands, like maybe an A4 laminated sheet, day one bullet points.” (IDWG AEP)

There were some questions raised around having audio recordings available to participants of the groups' discussions, and the ethics of sharing, which were at times, some personal experiences and anecdotes. It was suggested that perhaps a written and recorded summary of the day be made available to participants. There could also be scope to have participants have some input on any potential recordings that would be made available.

“And if we were to do it again, I'd be looking at members to do that recording.” (IDWG AEP)

C) Length and structure

Both the IDWG AEP Officer and the Human Rights facilitator agreed that the course should be delivered in a different structure or format to its current iteration, however, there was no optimal delivery option. The needs of people with dementia as learners were considered - this is the first time The ASI has delivered a course for

people living with dementia. All courses are focused on those who care and support.

"It could be three mornings in a row. I think two mornings is too short. I think four mornings over two weeks is too long... I'd love to sit down with the facilitator who's doing it. Look at the course, content... I'd say three mornings would be perfect." (IDWG AEP)

"Too long- some participants said they "could go on all day" but most were open about being very tired, and honestly, all of them were fading about an hour before lunch. Suggesting 2-hour modules with a 10-minute break for future- has further advantage of being more replicable by other presenters" (HRF)

The facilitator also noted that, at times, it was a challenge to keep people engaged in longer sessions:

"It was an effort for all of us to keep the energy up in the room. It was tiring for them, but you could see them enjoying it, and you could occasionally see like you can nearly see little light bulbs going off over people's heads, but you could see people having the craic with each other, and you could see relationships forming."(HRF)

The use of music for both enjoyment and movement was also identified as a way to get participants engaged and get them learning about the concepts of human rights, including personal choice.

"I was thinking about ways that you could introduce both music and maybe the theme of personal choice into it... When people are signing up, you could ask them for their favourite music, and you, you know our musical choice. And then, like each break time you could have a different person."(HRF)

There was also the suggestion that the modules could be delivered at different times, delivered in the context of other things that might be happening in Ireland around new legislation or policies.

"If there's gonna be an awful lot of talk about assisted decision making. And if people are specifically interested around the system, decision making, you could do the one or two slot session on decision making." (HRF)

It was noted that icebreaker games that were utilised worked quite well in helping participants relax and get to know each other a little bit.

"It's getting to know individual people. I think that worked really well. People relaxed with that. So I think that worked very well. I think the videos are really good in the training as well because it gives people a chance to relax a bit." (IDWG AEP)

Recent research (Ingebrand & Hyden 2021) has shown that people living with dementia are capable of engaging

in novel learning and can remain active and engaged participants in this process. People living with dementia are a unique learning cohort, often with additional needs and varying cognitive levels and abilities. There are also often assumptions that the elements of lifelong learning do not extend to people living with dementia and that retrieval of memories can be difficult (Quinn & Blandon 2017). This, however, should not be seen as a barrier to learning or engagement. Moreover, these factors should be considered when designing and delivering a training programme for people living with dementia.

D) Support

The importance of support for participants attending the training, before, during and after was highlighted by both the Human Rights Facilitator and the IDWG AEP Officer. The level of support required to ensure participants felt comfortable was integral to the success of the training but may be a barrier if not resourced appropriately. The course was dependent on support from the wider ASI team.

“There is a resourcing issue. They're supported in all the practical, emotional ways during it, and they're connected and supported afterwards. And the family, you know, who are the gatekeepers... that's a huge piece of work...and it was done. But it was done at great pressure, you know...it probably requires more resourcing, and it requires to be really written into the fabric of the whole course, you know” (HRF)

Whilst the day-to-day support was acknowledged, there were also some unanticipated emotions that also required support by the IDWG facilitator.

“And I also think there was so much emotion in the room as well, which I hadn't really anticipated. So I think that means more support from our end that when people go home, are they okay? ...in case it does raise issues for them, it may have raised difficulties in their home life” (SK)

As part of this training, participants were not learning about abstract concepts; this course was teaching them about their rights as people with dementia, where many shared their stories and challenges. Grounding the learning in participant's everyday life has meant that learnings can be used in everyday life. Concepts are not abstract, therefore we hope are retained in the long term for some participants.

When asked about their feelings after the training completion, the issue of both logistic support but also emotional support was again highlighted as a caveat for future training.

“It was draining. I loved it, it was a privilege, and I would do it again tomorrow, but I was a wreck for a week afterwards. I can only imagine how demanding it was for the IDWG facilitator. It is not possible to deliver a course of this kind well without significant emotional investment as managing the emotional energy in the room is a critical component of successful course delivery.”

Both the Human Rights facilitator and IDWG AEP Officer noted the importance of briefing and debriefing as

integral to the training.

E) Reframing course aims / objectives

Both facilitators explored the idea of reframing the training course as one that seeks to empower people living with dementia to learn more about their human rights in a more practical way, with a focus on their feelings and empowerment, rather than sticking to strict learning objectives or outcomes. Due to the nature of many participants' dementias, retention of the content may not be the same; therefore the focus and emphasis may be revised.

"I'm not sure that learning outcomes is the right way to approach the course as there is an implication that for the module to be delivered successfully, participants must grasp or retain certain information. I think a better way to look at the course is via the maxim "a person may not remember what you say to them but will remember how you make them feel", while also offering accurate, interesting and relevant information which participants can access at will after the course is over, should they so wish" (HRF)

"The overall aim of the course might be stated as "To allow participants to experiment with applying a human rights lens to their own experiences as people living with dementia and consider whether it is helpful. This is done not only through the course content but through the manner of delivery and engagement: participants experience being treated with warmth and respect as individuals, being invited to share their experiences and opinions and having these heard and validated, and being offered as a matter, of course, any adaptations or support they need to facilitate their full participation"(HRF)

F) Positive outcomes

In reviewing lessons learned, the positive experiences which the course should offer could be broken down into three categories, all of which are essential to the success of the course. This format was highlighted by the Human Rights facilitator.

These three categories demonstrate areas where participants found enjoyment and suggestions for future training.

5. Section 3: Lessons Learned and Best Practices

One of the main purposes of this evaluation is not only to understand participants' and facilitators' perceptions of the training course but also how we can improve it for future delivery. There were a number of lessons learned from engaging and participating in the training but also informed from reflections.

1. Replicability - There was a level of variance in the number of participants who engaged and attrition across both sites. There was also variance in the timing of when participants completed the evaluation forms in the pre-training survey, which may have had an impact on their responses. In order to address this, we would suggest having a set time to collect data and additional staff on hand.
2. The unique learning needs of people living with dementia - this course is the first of its kind in Ireland and needs significant resources to recruit participants and support attendance. Learners required both emotional support (to calm nerves and offer reassurance) as well as practical support (liaising with family members, booking taxis and accommodation). It is estimated that for each person who attended, the IDWG AEP Officer spent approximately 4 hours in pre-planning.
3. Trainer skills - The trainer felt that a less experienced or skilled person may struggle to deliver this training to a cohort of people living with dementia.
4. Importance of briefing and debriefing for both the Human Rights facilitator and the IDWG AEP Officer - Arrange a meeting with the Human Rights Facilitator, the IDWG AEP Officer, and a member of the Steering Committee of the IDWG to be briefed ahead of time and develop a rapport
5. Role of formal co-facilitator - Ensure that there are co-facilitators, and people living with dementia to have a supporting role in delivering the training. This would help new members of the group to feel more at ease upon entering a new environment which may be daunting to them.
6. Supporters - Where practicable or necessary, supporters or carers of the person attending the training should be close to hand. This may or may not put people off attending the training, supporting a person to attend training but awareness that this might be needed. At each course, a member of The ASI team was present to spend time with carers and supporters.
7. Recruitment tool - This was an unexpected outcome of this training. We had several participants who were not members of the Irish Dementia Working Group prior to taking part in this training who have since registered their interest in joining the group.

6. Next Steps

Following on from the completion of the Rights Made Real training, The ASI hopes to create information materials to accompany the Rights Made Real awareness sessions. This will include a booklet and a short video if there is no suitable video already available. This booklet will outline key outcomes of the training, and we hope to develop a short video with participants' voices and experiences.

As this was the first training course also provided to people with dementia, we would also like to celebrate that achievement with participants on the course by way of a small celebration or graduation.

Following the completion of this evaluation, the next step of this work is to deliver the next round of training to people living with dementia, implementing our learnings.

7. Conclusion

Findings from both participants and facilitators helped inform this evaluation, with a number of suggestions for improvement of delivery and support. There was an overwhelming sense that the current structure should not be utilised, however, a more adaptive, agile approach taken in delivering training to people living with dementia. The focus of the training itself should also be on empowerment and decision-making, rather than learning objectives and outcomes.

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References

- Ingebrand, E., Samuelsson, C, & Hyden, L.C. (2021). People with dementia positioning themselves as learners. *Educational Gerontology*, 47(2), 47-62. <https://doi.org/10.1080/03601277.2020.1855501>
- Quinn, J. & Blandon, C. (2017). The Potential for Lifelong Learning in Dementia: A Posthumanist Exploration. *International Journal of Lifelong Education* [online] Accessed: 05/01/2023. <https://www.tandfonline.com/doi/full/10.1080/02601370.2017.1345994>

Appendix A - Revised structure to training course

Module 1: Dementia and Human Rights: what's the connection? (2 hours with a 10 minute break)

Aims:

- 1.To discuss concepts such as dementia, disability, stigma, discrimination and human rights and allow participants to become aware of their own attitudes and to hear from others.
- 2.To allow participants to experiment with applying a human rights lens to their own experiences as people living dementia and consider whether it is helpful.
- 3.To explore the concept of disability, medical and social models, and some legal definitions.
4. To introduce the UN Convention on the Rights.

Draft Outline:

- Is dementia a disability? – explore attitudes to dementia, disability, stigma.
- Definition of disability in UNCRPD and Disability Act
- Medical v. social model of disability (video to be sourced)
- Some UNCRPD key articles and case examples
- Why might it be useful to think of dementia as a disability?

Module 2 : Equality and Discrimination (2 hours with a 10 minute break)

Aim:

1. To discuss the concepts of equality and direct and indirect discrimination and allow participants to apply these to their own experience.
2. To introduce key aspects of Irish Equality Law (Equal Status Act and Employment Equality Acts) and examine some examples.
3. To introduce and explore the concept of “reasonable accommodation” in relation to disability and invite participants to consider its usefulness in relation to their own experience.

Draft Outline:

- Meaning of equality- treating the same situations the same and different situations differently
- Equal Status Act (covers access to goods and services) and Employment Equality Act (covers employment)
- Definition of discrimination – 9 grounds of discrimination in Irish Equality law; direct and indirect

discrimination

- Have you ever experienced discrimination because of having dementia?
- Concept of “reasonable accommodation” in relation to disability- what might reasonable accommodation look like for a person living with dementia.
- Some examples of Equal Status Act caselaw/stories.

Module 3: Decision-making Part 1. (2 hours with a 10 minute break)

Note: this will need to be adapted slightly after full commencement of the ADM Act 2015 and it might be possible to condense it into one module- at the moment discussing outdated attitudes and legislation and stigma around impaired decision-making is essential and generates quite a bit of discussion.

Aims

1. To introduce the current legislation on decision-making in Ireland the Regulation of Lunacy Act 1871/Ward of Court system and discuss the outdated attitudes and stigma which it reflects
2. To introduce Article 12 of the UNCRPD and explain why Ireland’s current legislation is incompatible with it.
3. To introduce key provisions of the Assisted Decision-Making Act 2015 including the presumption of capacity, the right to make unwise decisions, the right to be supported to exercise capacity and the importance of “will and preferences”
4. To explore the functional definition of capacity (time- and decision- specific, four “ingredients” of capacity).

Draft Outline

- Regulation of Lunacy Act 1851 – what attitudes to mental health and disability does it reflect? What is wrong with the Ward of Court system?
- Article 12 of the UNCRPD – no-one shall lose legal capacity by reason of having a disability- what does this mean?
- How does the ADM Act fix the problems with the Irish system (and why is it not quite law yet?)
- Presumption of capacity and right to support to exercise capacity
- Definition of capacity- functional approach
- Unwise decisions and “Will and preferences”- video and discussion.

Module 4: Decision-making Part 2 (2 hours with a 10 minute break)

Aims

1. To review key impact of ADM Act
2. To discuss current options for future planning and protecting decision-making autonomy- Enduring Power of Attorney,
3. To outline new options under the ADM Act: Advance Healthcare Directives and the 3 new options for decision-making support, Decision-making Assistant, Co-Decision-Maker and Decision-Making Representative.
4. To explore the difference between “will and preferences” as opposed to “best interest” decision-making and discuss the importance of communicating our wishes and preferences.

Draft Outline

- Quick review of key concepts from Decision-Making Part 1
- Outline of how Enduring power of Attorney works with opportunity to discuss personal experiences.
- Outline new options and how they might work
- Will and preferences – video about decision-making process and discussion
- “Two Truths and a Lie” - a bit of fun and also practice at communicating who we are as opposed to who people think we are!

Module 5: Human Rights Based Approaches (HRBAs) (2 hours with a 10 minute break)

Aims

- 1.To introduce the idea of human rights based approaches and some key human rights principles
 2. To discuss some key human rights and where they are set out.
 3. To introduce the concept of “rights-holders” and “duty-bearers”
- 2.To introduce the FAIR tool as a way of analysing what needs to happen from a human rights perspective in any particular situation
 3. To apply the FAIR tool to a video scenario and discuss.

Draft Outline

- What is a HRBA?
- Some key principles of human rights: eg proportionality, fair procedures, participation.

- Define “rights-holders” and “duty bearers”
- The FAIR approach: Facts, Analysis of Rights, Identification of Responsibilities, Review
- Apply the FAIR approach to a video scenario- what are the facts, what are the rights involved, who needs to do what?