ORIGINAL ARTICLE

JARID _Journal of Applied Research in Intellectual Disabilities_ **bild** _Published by the British Institute of Learning Disabilities_ WILEY

Shared decision making with frail people with intellectual disabilities in the palliative phase: A process evaluation of the use of the In-Dialogue conversation aid in practice

H. W. Noorlandt[1] [ORCID] | I. J. Korfage[1] | F. M. A. J. Felet[2] | K. Aarts[3] |
D. A. M. Festen[4] | C. Vrijmoeth[5] | A. Van Der Heide[1] | M. A. Echteld[6,7]

[1]Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, Zuid-Holland, The Netherlands

[2]Expert by Experience, Breda, Noord-Brabant, The Netherlands

[3]Care facility for people with intellectual disabilities, Amarant, Breda, Noord-Brabant, The Netherlands

[4]Department of General Practice, Intellectual Disability Medicine, Rotterdam, Erasmus MC, University Medical Center, Rotterdam, Zuid-Holland, The Netherlands

[5]Centre for Research and Innovation in Christian Mental Health Care, Eleos/De Hoop GGZ, Hoevelaken, Utrecht, The Netherlands

[6]Palliative care project director, Prisma Foundation, Waalwijk, Noord Brabant, Netherlands

[7]Avans University of Applied Science, Expertise Centre Caring Society, Breda, Noord-Brabant, The Netherlands

Correspondence
H. W. Noorlandt, Department of Public Health, Erasmus MC, University Medical Center Rotterdam, PO Box 2040, 3000 CA Rotterdam, The Netherlands.
Email: h.noorlandt@erasmusmc.nl

Funding information
The Netherlands Organization for Health Research and Development

Abstract

Background: This study reports the process evaluation of the In-Dialogue conversation aid to facilitate shared decision-making with people with intellectual disabilities in the palliative phase.

Methods: Training for In-Dialogue was evaluated by 53 support staff members through questionnaires. The use of In-Dialogue in four residential care facilities for frail people with mild to severe intellectual disabilities was evaluated with semi-structured interviews with five relatives, nine support staff and three people with intellectual disabilities.

Results: Most participants considered the training helpful to apply shared decision-making. Sixty-three people with intellectual disabilities participated in In-Dialogue conversations. Almost all interviewees stated that these conversations provided additional insight into people's concerns and preferences. Involvement of people with profound intellectual disabilities and their relatives appeared to be challenging.

Conclusion: Conversations about illness and the end of life appeared to be feasible with the In-Dialogue conversation aid and provided insight into people's experiences and preferences.

KEYWORDS
palliative phase, people with intellectual disabilities, process evaluation, shared decision making, use of In-Dialogue

1 | INTRODUCTION

During the last few decades, palliative care has become recognised as a central tenet to improving end-of-life care for people of all ages. The World Health Organization defined palliative care as 'an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness' (World Health Organization, 2020). Recently there has been more focus on palliative care for people with intellectual disabilities. In 2016, the Taskforce on Intellectual Disabilities of the European Association for Palliative Care published consensus-based norms on how policy, research and practice can improve palliative care for people with intellectual disabilities

(Tuffrey-Wijne et al., 2016). One of these norms states that people with intellectual disabilities should be involved in end-of-life decision-making and should have all the support they need to do so (Tuffrey-Wijne et al., 2016). Article 12 of the Convention on the Rights of Persons with Disabilities underlines this norm and states that people with intellectual disabilities have the right to be recognised by law as a person equal to others (United Nations, 2006).

An essential element of palliative care is shared decision-making (SDM). SDM is an approach in which healthcare providers and patients discuss relevant care and treatment options and jointly decide which treatment option best fits the patients' wishes, needs and preferences (Stiggelbout et al., 2012). Getting to know these wishes, needs and preferences is challenging, and even more so when people have intellectual disabilities. It can be difficult to identify people's preferences when there are communication challenges or when people can only express themselves non-verbally (Kirkendall et al., 2017; Voss et al., 2019; Vrijmoeth et al., 2016). Furthermore, support staff found it difficult to have conversations about illness and death with people with intellectual disabilities (Bekkema et al., 2014; Voss et al., 2017). People with intellectual disabilities are often not actively involved in decision-making processes in the last phase of their lives due to communication challenges, assumptions that people with intellectual disabilities will not be able to handle difficult conversations, assumed lack of capacity and the lack of advance care planning skills of healthcare professionals (Kirkendall et al., 2017; Noorlandt et al., 2020; Voss et al., 2019; Wagemans et al., 2010). Research shows that people with intellectual disabilities do want to be involved in the decision-making process about their care (Bekkema et al., 2016; McKenzie et al., 2017; Tuffrey-Wijne et al., 2016).

To support the SDM process for people with intellectual disabilities, we developed the conversation aid In-Dialogue through a Delphi procedure (Noorlandt et al., 2021) and subsequent feedback rounds with experts by experience, support staff and graphic designers (Noorlandt et al., 2021). To facilitate the use of In-Dialogue, we developed an e-learning and a training for support staff on how to apply In-Dialogue in practice. Most studies with people with intellectual disabilities around end-of-life conversations have been conducted with people who were in good health and not yet in the palliative phase (McEvoy et al., 2012; Stancliffe et al., 2016; Stancliffe et al., 2021). Except for McKenzie's study (McKenzie et al., 2017), our study is the only other to involve people with intellectual disabilities who were frail and had a limited life expectancy as participants. In four Dutch residential care facilities for frail people with mild to profound intellectual disabilities staff were invited to follow the In-Dialogue e-learning and training. Subsequently, trained staff members applied In-Dialogue for a year. In this paper, we describe the process evaluation, and we answer the following three questions: (1) Is the In-Dialogue aid a feasible and applicable tool to assist support staff in involving people with intellectual disabilities in the decision-making process in their palliative phase? (2) What added value /benefit does In-Dialogue have for support staff, relatives and people with intellectual disabilities? (3) What were barriers and facilitators in the process of training support staff in working with In-Dialogue and the application of In-Dialogue in practice?

2 | METHODS

2.1 | Design and setting

We performed a descriptive observational study in four Dutch residential care facilities for people with intellectual disabilities. Within these facilities, we selected sites where many of the residents were frail and likely to enter or be in the palliative phase.

In the Netherlands, people with intellectual disabilities in residential care facilities are mostly supported by staff with a social work background. All support staff are expected to provide support with daily living activities.

A general practitioner (GP) or a specially trained intellectual disabilities physician is responsible for the medical care. The GP and intellectual disabilities physician work closely together with psychologists, nurses, physiotherapists, occupational therapists, speech therapists, and other professionals. In addition, one of the four participating care facilities has a hospice for people with intellectual disabilities.

Currently, in the Netherlands, it is still care facility-specific whether and how palliative care and advance care planning is organised within a facility. In the care facilities that participated in this study, the intellectual disabilities physician, nursing specialists and psychologists, are often involved in palliative care decision-making together with support staff and family.

2.2 | Inclusion criteria

To be included in the In-Dialogue study, people with intellectual disabilities had to be in the palliative phase. We operationalised this as a negative answer by a support staff member of that site, sometimes supported by a behaviourist of that site, to the Surprise Question: 'Would you be surprised if this person died within a year?' (Romo & Lynn, 2017). This question might be difficult to answer for people with intellectual disabilities. Therefore, also one or more of the following criteria had to be met: having Down syndrome and being 50 years of age or over, being 70 years of age or over, having a chronic condition, and/or 'a gut feeling' of the support staff. To clarify, people with intellectual disabilities were the actual study participants in this study. Another inclusion criterium was that a person who was important to the person with an intellectual disability, for instance a relative, had to be able and willing to complete a questionnaire on how the person with an intellectual disability had been involved in making decisions about treatment and care.

2.3 | The In-Dialogue intervention

The In-Dialogue intervention consists of an e-learning and a four-hour group training session.

The In-Dialogue conversation aid is presented in a box containing a pad similar to a board game, see Figure 1. The box includes 13 conversation cards, addressing people with intellectual disabilities with
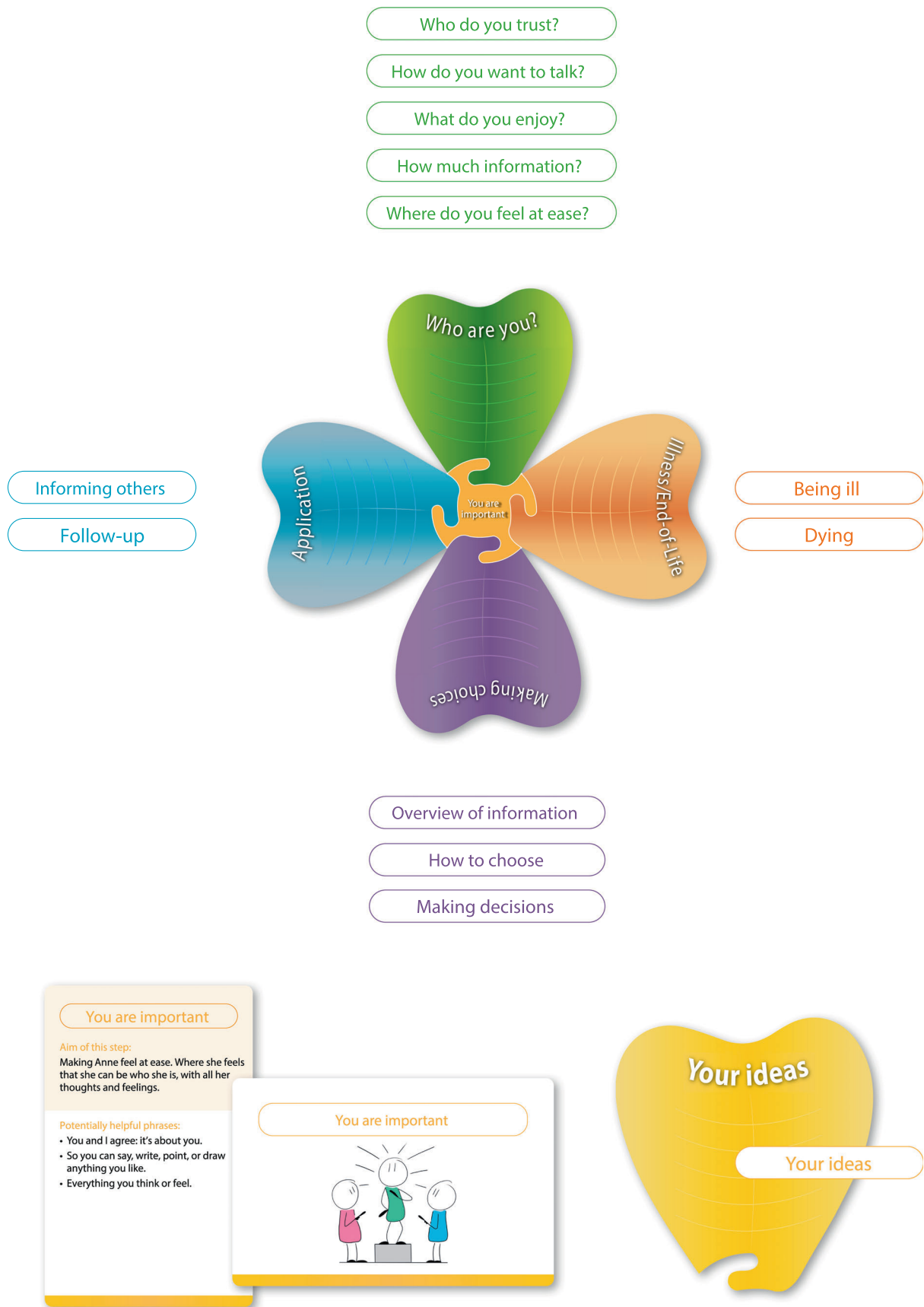
Who do you trust?

How do you want to talk?

What do you enjoy?

How much information?

Where do you feel at ease?

Who are you?

Illness/End-of-Life

Being ill

Dying

Application

Informing others

Follow-up

You are important

Making choices

Overview of information

How to choose

Making decisions

You are important

Aim of this step:
Making Anne feel at ease. Where she feels that she can be who she is, with all her thoughts and feelings.

Potentially helpful phrases:
- You and I agree: it's about you.
- So you can say, write, point, or draw anything you like.
- Everything you think or feel.

You are important

Your ideas

Your ideas

FIGURE 1 The In-Dialogue conversation aid.

helpful phrases, 50 supporting illustrations with the option of accompanying text, a workbook (also available digitally) and a manual. The manual was developed to give support staff and/or parents tools to get started with In-Dialogue. For each theme, all conversation cards are discussed. For each card, the purpose of the card is described and phrases are given that can help facilitate the conversation. In addition, the manual provides additional tips to facilitate the conversation with the person with an intellectual disability. Topics that came up varied, for example, one resident discussed the death of a family member that made a big impression on him, a resident wanted to take a look at the ICU where he had been lying for a long time, and several people gave their preferences around their funeral. For example, one resident wanted plastic flowers at her funeral because they never decay. The aid consists of five petals. The main themes, as described on these petals, are: (1) Who are you; (2) Illness and end-of-life; (3) Making choices; and (4) Application. The fifth petal contains the theme 'your ideas'. The purpose of this petal is to find out whether everything of interest to the person with intellectual disability has been discussed. In-Dialogue is always performed with the first four petals; the fifth petal is optional. Therefore, the fifth petal is not studied in this study. To encourage people with intellectual disabilities to express what they think, every conversation starts with reminding them of the guiding principle named 'you are important'. For more details about the In-Dialogue intervention, see (Noorlandt et al., 2021).

The In-Dialogue intervention is introduced to the person with an intellectual disability and to their important person during scheduled conversations during which the person with an intellectual disability receives their own In-Dialogue box. The support staff member explains that the resident can make the In-Dialogue box their own, for instance by writing their name on the box or decorating it. In addition, the first of the four themes of In-Dialogue is introduced; 'Who are you'. In the second conversation with, if possible, for example, relatives, the support staff member introduces the second theme of In-Dialogue 'Illness and End-of-Life'. If preferred, additional people can be invited to join In-Dialogue conversations. The content of the conversation depends on the ability of the person with an intellectual disability to actively participate in it. The support staff member is asked to write down the most important findings, in the workbook and the digital form at the end of each conversation to indicate where the conversation could be resumed next time. Following the In-Dialogue training, support staff applied In-Dialogue during a year, after which the feasibility and applicability of In-Dialogue was discussed with a subset of them, in semi-structured interviews. To give more clarity on who the participants are referred to in the text, the two different phases of application will be mentioned. Phase 1. Preparation for In-Dialogue conversations, where the participants are the support staff and Phase 2. Implementation of the In-Dialogue conversations, where the participants are the people with intellectual disabilities.

2.4 | The In-Dialogue training Phase 1 support staff

An e-learning module was developed, which covered shared decision-making, palliative care, communication, different ways people want to think about and cope with death, and the In-Dialogue aid. The group training consisted of two parts. Part 1 reflected on the e-learning and further explained the In-Dialogue aid. During part two, participants practiced having an In-Dialogue conversation with a training actor. The content of the training was adjusted to the participants' palliative care knowledge. The training is designed as a 'train-the-trainer' program, whereby participants are trained themselves and are given the tools to deliver the training to their colleagues.

2.5 | Data collection

For the operationalization of the process evaluation, we used the Medical Research Council Guidance (Moore et al., 2015) and the RE-AIM model (Glasgow et al., 1999) for guidance. Among other things, the guidelines allowed us to operationalise important concepts such as 'adoption' and 'implementation'. In our study, adoption is about the characteristics of the participants of the In-Dialogue training and In-Dialogue conversations and the reasons why the In-Dialogue conversations were adopted or not. Implementation refers to the extent to which the intervention was carried out (Glasgow et al., 1999), how many people were trained, how many eligible people with intellectual disabilities and relatives participated in the In-Dialogue study, and the remarks aforementioned stakeholders had using the In-Dialogue tool. Furthermore, we examined what could be improved on the design of In-Dialogue and the application of the conversation aid in practice by interviewing people with intellectual disabilities, relatives and support staff. Finally, we explored the effectiveness of the study by examining contextual factors that could influence the impact and implementation of the conversation aid (Moore et al., 2015). Contextual factors were queried by asking support staff, relatives and people with intellectual disabilities about the feasibility, applicability and desirability of the In-Dialogue instrument.

In operationalising the concept of adoption, for example, themes such as beginning to use In-Dialogue, content of In-Dialogue, and talking about death and dying, appeared to be important to inquire.

2.6 | Questionnaires to evaluate the In-Dialogue training Phase 1-support staff

After the In-Dialogue training, participants were asked to complete a questionnaire of 41-items. In total, 97 support staff members from 16 sites from four residential care facilities, attended the In-Dialogue training. Of these support staff members, 53 (55%) completed the training evaluation questionnaire. Of the 53 questionnaires, 24 were completed after attending a digital training, and 29 after a face-to-face training.

In the questionnaire the participants' opinion of the e-learning, the training and the knowledge gained was inquired. Respondents used a 4-point Likert scale (completely agree, agree, disagree, completely disagree), to respond to the first 16 statements about e-learning and training. In addition to these 16 statements, respondents could use a 3-point Likert scale (too long, just long enough, too short) to answer five more questions on the duration and group size of the training. Furthermore, four open-ended questions were asked on what participants missed in the e-learning and training and support they needed to use In-Dialogue in practice. An open field made it possible for participants to write down additional questions or comments. In addition to these items, participants could rate the nine different components of the training at a scale from 1 to 10. Finally, there were seven other items about the personal characteristics of the participants, such as age, work experience, and education.

2.7 | Semi-structured interviews Phases 1 and 2-support staff and people with intellectual disabilities

Interview participants were purposively sampled since we wanted to evaluate the use of In-Dialogue with a diverse group in terms of relationship to the person with an intellectual disability, age, degree of intellectual disability of their relative/important person and type of residential care facility where this person lived. We asked support staff, who followed the In-Dialogue training, and relatives and people with intellectual disabilities, who worked with the In-Dialogue intervention, if we could approach them to answer questions about the use of In-Dialogue. Interviewees were informed that the content of the interview would not be shared with support staff or residents. Furthermore, 17 interviews were conducted; 11 by one of the researchers (HN) and 6 by a caregiver (KA). Eleven interviews were conducted online, four face-to-face, one by phone, and one interview was conducted in writing. The interviews lasted 30–60 min and were conducted between April and November 2021. After 17 interviews no more new themes emerged from the interviews and saturation of the data had been reached. Interviews were conducted with five relatives, nine support staff members and three people with intellectual disabilities. Quotes selected from the interviews were translated by (HN) and checked for accuracy by the research team (IK, ME).

All interviews were conducted using an interview guide based on two main questions: (1) How was In-Dialogue applied? (2) How did the participants experience working with In-Dialogue? For the interviews with people with intellectual disabilities these questions were adapted by one of the researchers (FF) who is an expert by experience with the aim of ensuring that questions would be understandable for people with intellectual disabilities. The research team (HN, IK, ME) regularly discussed the collected data and adjusted the interview guide accordingly.

2.8 | Data analysis

The data collected from the semi-structured interviews were analysed using thematic analysis (Boeije, 2005) using the interview guide as a framework for the codes. One researcher (HN) read the transcripts of six interviews, and examined whether the codes fit under the pre-identified themes, which were discussed and adapted with the research team. The codes were organised into an initial coding tree, by going back and forth through the themes and the transcripts, using the constant comparative method (axial coding). The initial coding tree was tested by (HN) on transcripts of another two interviews; the connections between the codes were discussed with the research team and the coding tree was adjusted accordingly. Subsequently, all transcripts were coded with the final coding tree by (HN). In consultation with the other researchers (IK, ME, KA, FF) the data were interpreted and the main themes were selected (selective coding). See Table 1 for the main themes. Next, the themes found were ordered according to phases of the application: Phase 1. Preparation for In-Dialogue conversations, Phase 2. Conducting the In-Dialogue conversations.

To analyse the evaluation of the training, we entered the data from the evaluation forms for the In-Dialogue training into SPSS version 25 to obtain descriptive statistics. We tested the differences in total scores between the face-to-face and the digital groups using the Mann–Whitney U test. In the analysis of the further data, we show the results of the hospice staff separately, since their experience and training differ significantly from those of other support staff. We tested mean differences between the hospice support staff and all other support staff of gaining insight into how to apply In-Dialogue in practice, the differences in mean grades for the training and the differences between the increased knowledge about shared decision making scores.

2.9 | Ethics

Participants were able to answer the evaluation questionnaire anonymously. Participants' informed consent to participate in the interviews was audio-recorded (eight times), or given in writing (nine times). The participants with intellectual disabilities that (KA) interviewed were able to give their own consent. Approval of this study was obtained from the Erasmus MC, University Medical Center Rotterdam research ethics committee (METC-2018-1683).

TABLE 1 Main themes coding.

Main themes	Identified codes grouped per main theme
1. Preparation of In-Dialogue conversations	Introduction of the tool to clients
2. Using In-Dialogue in practice	Involving family Content of the tool Barriers and facilitators in the training of and working with In-Dialogue
3. Successful application of In-Dialogue	Added value using In-Dialogue

TABLE 2 Characteristics of staff members in the In-Dialogue training who completed the questionnaire ($n = 53$).

Staff characteristics	All participants	Participating care facilities				
		Facility 1 $n = 7$	Facility 2 $n = 21$	Facility 3 $n = 15$	Facility 4 $n = 3$	Hospice $n = 7$
Mean age (years)	41.5	39	41	44	38	41
Job title	n (%)					
Key worker	43 (83)	6	17	13	2	5
Supportive worker	7 (13)	1	3	1	1	1
Assistant worker	1 (2)	-	1	-	-	-
Care manager	1 (2)	-	-	1	-	-
Missing	1	-	-	1	-	1
Mean years of work experience with people with intellectual disabilities, range 1–44.	16.4	13	14	18.5	19	20
Missing		-	-	1	-	-
Experience with providing palliative care						
Yes	51 (96)	6	21	15	2	7
No	2 (4)	1	-	-	1	-
Trained in palliative care						
Yes	37 (71)	4	12	11	3	7
No	15 (29)	3	8	4	-	-
Missing		-	1	-	-	-

3 | RESULTS

3.1 | Phase 1: Preparation for In-Dialogue conversations

3.1.1 | Characteristics of participants in the In-Dialogue training who completed the questionnaire

The majority of the 53 participants who completed the evaluation questionnaire were key workers, 7 of the participants were staff members of a hospice. Most trained support staff members, excluding hospice staff, had between 6 and 15 years of experience in working with people with intellectual disabilities. All but two participants, had previous experience in providing palliative care. Over 70% of the participants had received palliative care training, see Table 2.

3.1.2 | Applicability of In-Dialogue after attending the In-Dialogue training

Of the 53 people, all but three people had a better understanding of how to apply In-Dialogue in practice after attending the training. Furthermore, almost everyone planned to use the In-Dialogue box in practice. Of the participants, almost 80% felt that their knowledge of shared decision-making had increased after attending the training and that the In-Dialogue training helped them to apply shared decision-

making in practice. A Mann–Whitney U test revealed no significant difference between the rating of ranks between the face-to-face and the digital In-Dialogue training, $U = 288$, $p = 0.35$. See Table 2 for more details on the evaluation.

Gained insight in how to apply In-Dialogue in practice did not differ between hospice staff and other support staff, $U = 89.5$, $p = 0.09$. Hospice staff gained less knowledge about shared decision-making than other staff, $U = 87$, $p = 0.03$. No significant difference was seen between the ranks of the grades given to the In-Dialogue training between both groups, $U = 104$, $p = 0.11$. See Table 3 for more information.

After the In-Dialogue conversations were completed, interviews were conducted with support staff, people with intellectual disabilities and their relatives. See Table 4 for an overview of the characteristics of the interviewees.

3.1.3 | Introduction of the tool to clients

Support staff reported that they adapted the introduction of In-Dialogue to the preferences and interests of the person with an intellectual disability. Some support staff indicated that the In-Dialogue box was a bit too childish for the people with intellectual disabilities they worked with. They indicated that it might help when the box was introduced as a remembrance box. According to support staff, the illustrations and the clearly recognisable box were actually attractive to use for other people with intellectual disabilities.

TABLE 3 Responses to the evaluation questionnaire of support staff who participated in the In-Dialogue training (n = 53).

Questionnaire item	Response options	Support staff responses (N [%])	
		Care facility 1–4	Hospice
This training helps me to apply shared decision-making in practice	Strongly agree	7 (16)	-
	Agree	34 (77)	5 (71)
	Disagree	3 (7)	2 (29)
	Missing	2	-
I have more insight into how I can apply In-Dialogue in practice because of the training	Strongly agree	14 (31)	1 (17)
	Agree	31 (67)	3 (50)
	Disagree	1 (2)	2 (33)
	Missing	-	1
I am planning to use the In-Dialogue box	Strongly agree	18 (39)	1 (14)
	Agree	27 (59)	6 (86)
	Disagree	1 (2)	-
My knowledge of shared decision-making increased after this training	Strongly agree	9 (20)	-
	Agree	28 (60)	3 (43)
	Disagree	9 (20)	4 (57)
Average grade for the training (1–10)		7.5	7.1

TABLE 4 Distribution of respondent characteristics across care facilities.

Respondent characteristic	Participating care facilities				
	All participants	Care facility 1	Care facility 2	Care facility 3	Care facility 4
Sex					
Male	6	1	-	1	4
Female	11	5	3	-	3
Respondent category					
Support staff	9	5	1	-	3
Relatives	5	1	2	1	1
Person with an intellectual disability	3	-	-	-	3
Residential setting					
Institutional setting	7	2	3	1	1
Community-based home	8	2	-	-	6
Hospice	2	2	-	-	-

3.2 | Phase 2: Using In-Dialogue in practice

Seventy-two people with intellectual disabilities and or their relatives provided informed consent to participate in the In-Dialogue study. Three of these people were excluded from the study after enrollment due to relocation, having too much death and grief in the personal environment of the person with intellectual disabilities, and the death of a legal representative. Sixty-nine people were included in the study. Of these, 60 people with intellectual disabilities and or their relatives had In-Dialogue conversations and nine participants were unable to participate in the In-Dialogue conversations. Of the people who participated in the In-Dialogue conversations, 56 people completed the questionnaire. Of the people who could not participate in the In-Dialogue conversations, seven people completed the evaluation questionnaire, bringing the total number of participants in the study to 63. See Table 5 for an overview of the characteristics of the participants of the In-Dialogue conversations. It would have been interesting to have had more data on characteristics of people with intellectual disabilities such as communication skills and other health data but this information was not collected.

TABLE 5 Characteristics of people with intellectual disabilities and relatives who participated in the In-Dialogue conversations.

Participating care facilities	Care facility 1 n = 23	Care facility 2 n = 20	Care facility 3 n = 20	Care facility 4 n = 11
Number of sites	5	5	3	3
Characteristics of relatives, people with intellectual disabilities and important others who conducted and participated in the In-Dialogue conversations				
Conversations conducted with				
Relatives	2	11	5	1
Mentor	2	-	-	-
Person with an intellectual disability	18	8[a]	9	9[a]
Intention to treat	1	1	6	1
Degree of intellectual disability of the participants with intellectual disabilities				
Severe/Profound intellectual disabilities	3	5	8	-
Mild/Moderate intellectual disabilities	18	11	7	11
Average number of conducted In-Dialogue conversations per person with an intellectual disability	1.7	2.2	1.2	2

[a]Not all reports make clear whether the person with an intellectual disability actually attended the conversations. When this is unclear, they have not been included in this table.

3.2.1 | People who could not participate in the In-Dialogue conversations

Intention to treat (n = 9) means that the participants were included in the study, but the In-Dialogue conversation has not (yet) taken place. In five cases, the site was too burdened with COVID-19 care and changes in support staff to be able to conduct the In-Dialogue conversations. In one case, it was not possible to conduct the conversations with the person with an intellectual disability since, according to support staff members, the conversations would be too burdensome for the person since the person had experienced many bereavements in his close circle. In one case In-Dialogue was presented as a game where after the first question, the person with an intellectual disability did not want to do the In-Dialogue conversations anymore. In another case, the relatives of the person with an intellectual disability could not be reached to schedule an In-Dialogue conversation and in the last case the person with an intellectual disability had died before the interviews could take place.

3.2.2 | Involving family

People with intellectual disabilities who were interviewed indicated that they would like to invite family members to In-Dialogue conversations where important decisions are made. Some relatives liked being invited to have In-Dialogue conversations and to talk about illness and end-of-life, and to be able to ask the questions they had been wondering about for a while. A relative stated that: 'I liked talking about being ill, dying, because normally there is no room for it, my son has only been living at this location for a year and there is much more room for it in this setting [having an In-Dialogue conversation] than there ever was before. You're often a little uncertain about how to proceed and what if something happens and then it's nice to know what the options are. And if he got really ill where would he go or if he could stay'. (quote 17). A support staff member added that: 'It was

also nice for us as a team that we no longer had to figure everything out, but that a clear document has already been made for this [to facilitate the conversation about illness/end-of-life]' (quote18).

3.2.3 | Content of the tool

Support staff found applying In-Dialogue helpful in several ways. A support staff member indicated that: 'sitting down together, listening carefully, writing down what the resident said, making new appointments and the box that the person with an intellectual disability can make their own, were all ingredients for having in depth conversations' (quote 32). A resident indicated that the In-Dialogue conversations 'are serious conversations, where everything of importance is discussed in a loose way' (quote 33). A support staff member of the hospice indicated that even though 'some pretty heavy topics were discussed, the whole conversation looked cozy, with a cup of coffee, the conversation cards and the box on the table, It was an inviting way to have a serious conversation' (quote 22). Another employee of the hospice found In-Dialogue pleasant to use, because it made her follow a certain order that you are able to visualise for the person with an intellectual disability. That way she could make clear what the next steps were. Another employee of the hospice found that the conversation cards were very useful to her, because that way she knew what follow-up questions she could ask.

4 | BARRIERS AND FACILITATORS IN THE TRAINING OF AND WORKING WITH IN-DIALOGUE PHASE 1-SUPPORT STAFF

4.1 | The In-Dialogue training

Especially the practice with a training actor, was experienced as a valuable facilitator by most participants. Due to the pandemic, many

training sessions had to be conducted online. The interviews with the support staff (*n* = 9) showed that this was a barrier to practicing with the training actors. Some support staff indicated that it would be useful to have a training video in addition to the training itself with information on how to conduct an In-Dialogue conversation.

4.2 | Barriers and facilitators to In-Dialogue initiation

The interviews with support staff who used In-Dialogue, showed that it is important to have enough time for the conversations and to know the person with an intellectual disability, you are having the conversations with, reasonably well. 'You have to have someone who knows the client reasonably well. I think that's easier. To interpret correctly, whatever is said' (quote 49). Furthermore, support staff indicated that it is helpful to indicate beforehand that someone does not need to talk about things that someone finds difficult to talk about. In addition, that only the things which the person with an intellectual disability finds important, are written down. A relative stated that face-to-face conversations are facilitators for having In-Dialogue conversation, that way you can read someone's facial expressions and body posture.

Some support staff members indicated that both people with an intellectual disability and support staff themselves found it daunting to engage in the first conversation. They were not yet completely familiar with the method. Some support staff conducted the first In-Dialogue conversations together with a colleague so they could complement each other. After a few conversations, support staff knew more about what to expect. For example, the past medical experiences of the person with an intellectual disability provided points of discussion. One support staff member found it difficult to start conversations about being ill and end-of-life, because she noticed that the person with an intellectual disability only wanted to talk about it when he was very ill. It was difficult for this person with an intellectual disability to think about getting ill in the future. As his support staff member stated: 'But then he said: "I feel well, I'm not ill," so he took that a bit too literally. So at a certain point I made it more about getting older and that you can get ailments. He seemed to understand that a bit better' (quote 21). A staff member at the hospice indicated that they normally had conversations about being ill and end-of-life during the care moments. It felt a bit awkward for her to have the conversations with the conversation cards during a scheduled conversations.

Another support staff member would like to have some extra conversation cards to support the theme illness and end-of-life. One support staff member indicated that it would be good to address the conversation cards to support staff and relatives when people have severe intellectual disabilities, because the questions were addressed to the people with intellectual disabilities themselves now. The fact that questions are addressed to people with intellectual disabilities, also led one relative of someone with a severe intellectual disability, to indicate that he did not feel that In-Dialogue was meant for his relative because his relative could not verbally express herself. Yet there were also parents who, despite the fact that their child could not express herself verbally, tried to put themselves in the child's shoes in order to make the choices they thought their child would have made if she could talk. 'She is kind of our teacher, even if she doesn't have the words for it. (…) So that's also what we talked about in the In-Dialogue conversation, we as parents want to listen to what our child, what she can't tell with words, what for her is the preferred choice. When the four of us have to decide something, we rarely agree with each other. Whether it is about the colour of the wheelchair or her clothes, we rarely agree, and yet we believe we can all empathise with (daughter's name)' (quote 67).

4.3 | Added value using In-Dialogue

Support staff saw several reasons why having In-Dialogue conversations added value to practice. A staff member indicated that now the opinion of the person with an intellectual disability really came forward, whereas previously she had the idea that it was more her own opinion she heard back from the person with an intellectual disability. Sometimes residents did express preferences but were used to leaving the big decisions to others. It was up to support staff members to reassure residents that it is very good to have their own opinion then. 'Well a while ago, for example, we talked about euthanasia. (…)I don't want to go to a hospice. I don't want to go there. Then I'd rather go to a nursing home near here. But I'll leave that to my family, that decision, or to you. I don't know if that's possible' (quote 66). Furthermore, a support staff member stated that: 'the In-Dialogue conversations ensured that a person with an intellectual disability was very conscious of what he wanted at his funeral and that his wishes, which he also adjusted in between, were well recorded'(quote 39). According to a staff member, the In-Dialogue conversations created a bond of trust. This resulted in the person with an intellectual disability calling her when he was in the hospital to discuss his preference not to continue with chemotherapy. He had not dared to express this preference to the hospital staff. His wish was honoured.

Almost all interviewees reported that the In-Dialogue conversations had provided new information, or support staff had gotten to know the people with intellectual disabilities better through the conversations. In-Dialogue was found to be an appropriate tool for finding out the life history of people with intellectual disabilities. There were conversations about past hospitalizations and loved ones who had died. A relative stated that through the In-Dialogue conversations she gained a feeling that it was a collaborative process, with her daughter at the centre. A support staff member indicated that '[the In-Dialogue conversations] also teach you not to argue automatically from your own point of view'(quote 42). The same support staff member stated that she 'got to know the family situation and the life history of the resident better, that way I could sometimes better understand the choices that parents make'. 'In-Dialogue ensures that you look at the person with an intellectual disability from a distance and really see what is best for the resident and that certain insecurities of parents can be discussed' (quote 43).

5 | DISCUSSION

The aim of this process evaluation was to provide a more detailed understanding of the use of In-Dialogue in practice.

We found that In-Dialogue seemed to be feasible and applicable to apply in practice. The interviews with support staff showed that almost all In-Dialogue conversations had provided new information about the people with intellectual disabilities they cared for. It can be concluded that the In-Dialogue training and resources helped in a number of cases to engage people with intellectual disabilities in end-of-life conversations and gave support staff members the tools to facilitate this conversation.

For some support staff members, relatives and people with intellectual disabilities, it was difficult to talk about illness and death; they did not want to talk about this until the time was right. In three notes, this or a similar phrase emerged. Participants meant by 'the time is right', the moment when they would get seriously ill and it would become a real illness trajectory. 'The time is right' is a remarkable statement since all participants met our inclusion criteria and support staff would not be surprised if participants died within a year. Figuring out when 'it's the right time' to start the conversation about illness/death can be extra complicated since research shows that adults with intellectual disabilities find the inevitability of their own mortality the most difficult part to understand in relation to the concept of death (McEvoy et al., 2012; Stancliffe et al., 2016). Waiting until the person is seriously ill to discuss illness and end-of-life issues disadvantages and disqualifies the person with the illness because being seriously ill makes it particularly difficult for the person to learn to understand their own mortality. Instead, it can be argued that starting early with end-of-life education and information (well before the person is ill) is a better approach as it gives the person more time and a better chance to learn and understand. Others were willing to talk about these kinds of topics. Having enough time for the conversations and knowing the person you are having the conversations with well appeared to be facilitators.

Literature shows that support staff tend to find conversations with people with intellectual disabilities about illness and death difficult (Stiggelbout et al., 2012). Research conducted by Wiese shows that support staff would benefit from attending training sessions that teach them how to engage people with intellectual disabilities in conversations about dying and death and how to put protectionism behind them (Wiese et al., 2013). Other research showed that using an SDM tool in this process could be valuable (Bekkema et al., 2015; McKenzie et al., 2017; Vrijmoeth et al., 2018). McKenzie et al. found that involving people with intellectual disabilities in Advance Care Planning (ACP) had positive outcomes in terms of discussing matters at people's own pace, getting support to make their own choices, adapting the process to who they are, and, most importantly, to continue to shape their life the way they want to (McKenzie et al., 2017). The results from this process evaluation seem to confirm these findings. Through the In-Dialogue conversations, some people with intellectual disabilities became more aware of their preferences and wishes and in some cases a better relationship of trust was created in which the person with a disability really dared to indicate their views. The process evaluation also revealed some unexpected benefits. For example, In-Dialogue was found to be an appropriate tool for finding out the life history of people with intellectual disabilities. There were conversations about past hospitalizations and loved ones who had died. It is this kind of information that can be of great importance in making or supporting decisions about the end-of-life, as the studies by Bekkema and Watson also show (Bekkema et al., 2015; Watson et al., 2017). Based on past experiences, wishes and values of people with intellectual disabilities can become visible and current care can be adapted to these experiences.

When the palliative phase is identified in a timely manner, there is more time and space to ask about the wishes and values of people with intellectual disabilities and adjust care accordingly (Vrijmoeth et al., 2016). Research in the general population supports this, showing that early conversations about illness at the end-of-life can lead to positive family outcomes and benefits in quality-of-life (Bernacki et al., 2014). A study by McKenzie underlines this and shows that it is desirable to engage in ACP conversations as early as possible after diagnosis of a life-shortening condition (McKenzie et al., 2017). Kirkendall indicates the importance of reviewing wishes and preferences regularly, as these preferences can change significantly in the palliative phase (Kirkendall et al., 2017).

5.1 | Strengths and limitations

This study has several strengths. First, we used the Medical Research Council Guidance (Moore et al., 2015) and the RE-AIM model (Glasgow et al., 1999) for guidance in our process evaluation, which ensured that we conducted a complete and structured process evaluation. Among other things, the guidelines allowed us to better operationalise concepts such as 'adoption' and 'implementation' to the themes that were important to us in the process. Second, the semi-structured interviews were conducted by two different researchers and the support staff and relatives were purposively sampled based on their diversity in relationship to the person with an intellectual disability, age, degree of intellectual disability of their relative/important person and type of residential care facility. Third, we conducted interviews with people with intellectual disabilities. This approach provided more comprehensive and reliable insights, which benefited the reliability and relevance of the data obtained. Fourth, an expert by experience was involved in this study. Because the expert by experience himself receives care from one of the participating healthcare facilities, he could contribute to our study from a different perspective. For example, he was able to translate the interview questions and make them suitable for people with intellectual disabilities.

This study also has several limitations. First, in the interviews, support staff, family, hospice staff, and residents participated. In each of the groups, the number of participants is quite low. Furthermore, the interviewees included considerably more support staff and relatives of people with severe/profound intellectual disabilities than of people with mild/moderate intellectual disabilities. Every effort was

made to recruit a diverse group of people for interviews, in terms of the relationship someone has with the person with intellectual disability, age, degree of intellectual disability and type of institution where someone lives. Yet recruitment also depended on whether a person gave permission to be contacted again by the research team and the actual desire to engage in another interview with the researchers. This resulted in more relatives and support staff of people with severe/profound intellectual disabilities participating in these interviews sessions. Since we continued the interviews until we reached saturation of the data, we do not think this affected the data. Second, most support staff were acquainted in providing palliative care. This general knowledge may have contributed to the success of the In-Dialogue training. Thereby, the baseline knowledge of hospice staff is much more extensive than that of support staff members in 'regular' care facilities. Hospice staff members are constantly dealing with people who are in the palliative phase of their lives. For future research, it would be interesting to train a group of support staff members who have no or limited experience in providing palliative care so that it can be investigated how the In-Dialogue training then caught on. Third, due to the inclusion method we used, we included mainly participants who were in the beginning of their palliative phase. This was shown by the fact that almost all participants, after a year of working with In-Dialogue were still alive. For future research, it would be interesting to follow people with intellectual disabilities throughout their palliative phase until death. That way we can investigate how In-Dialogue is used in the different phases of palliative care and what the added value of this tool might look like. In this follow-up research, it would have been of interest to collect information on how many participants with intellectual disabilities knew they were ill or dying. This is important because discussion and decision-making about palliative care and end of life will likely be different for individuals with versus without that knowledge.

6 | CONCLUSION

In-Dialogue is suitable to apply in practice. The In-Dialogue conversations showed that it was possible to have conversations with people with intellectual disabilities who were in the palliative phase of their lives about topics such as their own illness and end-of-life. In fact, some people with intellectual disabilities even enjoyed talking about these topics and asked for follow-up In-Dialogue conversations themselves. Some minor adjustments are suggestions to better support use for people with severe intellectual disabilities. This recommendation of In-Dialogue is based on the application of In-Dialogue with support staff in residential care facilities. We recommend to conduct long-term research on the application of In-Dialogue in practice and on barriers and facilitators of long-term use of In-Dialogue. Furthermore it is important to examine how best to apply In-Dialogue with people with severe/profound intellectual disabilities who have difficulty expressing themselves verbally. After all papers surrounding the study have been published, all materials surrounding the In-Dialogue study will be released online via https://www.kennispleingehandicaptensector.nl/.

The English translation of In-Dialogue will also be available. Those interested can email us at samenspraakstappenplan@erasmusmc.nl.

CONFLICT OF INTEREST STATEMENT

The authors certify that they have no affiliations with or involvement in any organisation or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

H. W. Noorlandt https://orcid.org/0000-0002-4222-2213

REFERENCES

Bekkema, N., de Veer, A. J., Albers, G., Hertogh, C. M., Onwuteaka-Philipsen, B. D., & Francke, A. L. (2014). Training needs of nurses and social workers in the end-of-life care for people with intellectual disabilities: A national survey. *Nurse Education Today*, *34*(4), 494–500.

Bekkema, N., de Veer, A. J., Hertogh, C. M., & Francke, A. L. (2015). 'From activating towards caring': Shifts in care approaches at the end of life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians. *BMC Palliative Care*, *14*, 33.

Bekkema, N., de Veer, A. J., Hertogh, C. M., & Francke, A. L. (2016). Perspectives of people with mild intellectual disabilities on care relationships at the end of life: A group interview study. *Palliative Medicine*, *30*(7), 625–633.

Bernacki, R. E., Block, S. D., & American College of Physicians High Value Care Task F. (2014). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine*, *174*(12), 1994–2003.

Boeije, H. (2005). Het analyseren van kwalitatief onderzoek. *Huisarts en Wetenschap.*, *48*(13), 82.

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health*, *89*(9), 1322–1327.

Kirkendall, A., Linton, K., & Farris, S. (2017). Intellectual disabilities and decision making at end of life: A literature review. *Journal of Applied Research in Intellectual Disabilities*, *30*, 982–994.

McEvoy, J., Machale, R., & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *56*(2), 191–203.

McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S. (2017). "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. *Journal of Applied Research in Intellectual Disabilities*, 30, 1089–1098.

Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D., & Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ*, 350, h1258.

Noorlandt, H. W., Echteld, M. A., Tuffrey-Wijne, I., Festen, D. A. M., Vrijmoeth, C., van der Heide, A., & Korfage, I. J. (2020). Shared decision-making with people with intellectual disabilities in the last phase of life: A scoping review. *Journal of Intellectual Disability Research*, 64, 881–894.

Noorlandt, H. W., Korfage, I. J., Tuffrey-Wijne, I., Festen, D., Vrijmoeth, C., van der Heide, A., & Echteld, M. (2021). Consensus on a conversation aid for shared decision making with people with intellectual disabilities in the palliative phase. *Journal of Applied Research in Intellectual Disabilities*, 34, 1538–1548.

Romo, R. D., & Lynn, J. (2017). The utility and value of the "surprise question" for patients with serious illness. *CMAJ*, 189(33), E1072–E1073.

Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltes, G., Barton, R., & Clayton, J. M. (2021). Does talking about end of life with adults with intellectual disability cause emotional discomfort or psychological harm? *Journal of Applied Research in Intellectual Disabilities*, 34(2), 659–669.

Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltes, G., & Clayton, J. M. (2016). Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ? *Research in Developmental Disabilities*, 49-50, 47–59.

Stiggelbout, A. M., Van der Weijden, T., De Wit, M. P., Frosch, D., Legare, F., Montori, V. M., Trevena, L., & Elwyn, G. (2012). Shared decision making: Really putting patients at the Centre of healthcare. *British Medical Journal*, 344, 256.

Tuffrey-Wijne, I., McLaughlin, D., Curfs, L., Dusart, A., Hoenger, C., McEnhill, L., Read, S., Ryan, K., Satgé, D., Straßer, B., Westergård, B. E., & Oliver, D. (2016). Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A white paper from the European Association of Palliative Care. *Palliative Medicine*, 30, 446–455.

United Nations. (2006). Convention on the Rights of Persons with Disabilities. http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Voss, H., Vogel, A., Wagemans, A. M. A., Francke, A. L., Metsemakers, J. F. M., Courtens, A. M., & de Veer, A. J. E. (2017).

Advance care planning in palliative Care for People with Intellectual Disabilities: A systematic review. *Journal of Pain and Symptom Management*, 54, 938–960.

Voss, H., Vogel, A., Wagemans, A. M. A., Francke, A. L., Metsemakers, J. F. M., Courtens, A. M., & Veer, A. J. E. (2019). Advance care planning in the palliative phase of people with intellectual disabilities: Analysis of medical files and interviews. *Journal of Intellectual Disability Research*, 63, 1262–1272.

Vrijmoeth, C., Barten, P., Assendelft, W. J. J., Christians, M. G. M., Festen, D. A. M., Tonino, M., Vissers, K. C. P., & Groot, M. (2016). Physicians' identification of the need for palliative care in people with intellectual disabilities. *Research in Developmental Disabilities*, 59, 55–64.

Vrijmoeth, C., Echteld, M. A., Assendelft, P., Christians, M., Festen, D., van Schrojenstein Lantman-de Valk, H., Vissers, K., & Groot, M. (2018). Development and applicability of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI). *Journal of Applied Research in Intellectual Disabilities*, 31, 1122–1132.

Wagemans, A., van Schrojenstein, L.-d.-V. H., Tuffrey-Wijne, I., Widdershoven, G., & Curfs, L. (2010). End-of-life decisions: An important theme in the care for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54, 516–524.

Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 1022–1034.

Wiese, M., Dew, A., Stancliffe, R. J., Howarth, G., & Balandin, S. (2013). 'If and when?': The beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. *Journal of Intellectual Disability Research*, 57(10), 980–992.

World Health Organization. (2020). Definition of palliative care.