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## Advance Care Planning in Palliative Care for People with Intellectual Disabilities: a Systematic Review

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### ABSTRACT

**Context:** Advance care planning (ACP) is defined as a person-centred, ongoing process of communication that facilitates patients' understanding, reflection and discussion of goals, values and preferences for future care. There is evidence for the general palliative care population that ACP increases compliance with patients' end-of-life preferences and improves quality of care near the end of life.

**Objectives:** To gain insight into what is known about the use and effects of ACP in palliative care for people with intellectual disabilities (ID).

**Methods:** Four databases were searched systematically: PubMed, PsycINFO, Embase and CINAHL. A stepwise procedure was used to identify relevant studies based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement. The review included empirical quantitative, qualitative and mixed methods studies concerning people with ID who receive palliative care or who died non-acutely, and describing ACP. Methodological quality was graded using a critical appraisal tool.

**Results:** Fourteen studies were included. Most studies examined the perspective of professionals and/or relatives. None of the studies focused on the perspective of patients with ID. The studies concerned different elements of ACP, mainly decision-making and organizational policies. No effect studies were found. Obstructing factors were difficulties in recognizing palliative needs and

uncertainties among relatives and professionals about their roles and tasks in ACP. Conducive factors were good working relationships between professionals and relatives.

**Conclusion:** There are some indications that ACP could be useful for people with ID, but more knowledge is needed about whether and how ACP should be used.

## INTRODUCTION

### Background

According to the World Health Organization (WHO), palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (1). Intellectual disability (ID) is defined as a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. The disability develops before the age of eighteen and is often expressed using the IQ scale (with profound to mild intellectual disability covering the IQ range 0-70) (2).

People with ID have twice as many health problems as the general population (3). Moreover, the reported prevalence of chronic health conditions in children with ID is much higher than in the general population (4). Among them, there are individuals who are extremely fragile in terms of their health from birth on. Therefore, people with ID could have palliative care needs at an early stage of life. On the other hand, the life expectancy of people with ID has increased in line with that of the general population because of social and medical advances (5). This epidemiological development is linked to growing incidences of life-threatening illnesses at an older age, such as progressive cancer, chronic cardiovascular diseases, chronic lung diseases and dementia (6-8). Consequently, relatives and professionals increasingly have to cope with people with ID who are in need of palliative care.

Advance care planning (ACP) can be seen as an integral process of palliative care (9) and is defined as a person-centred, ongoing process of communication that facilitates patients' understanding, reflection and discussion of goals, values and preferences for future care (10). ACP has already been studied in various settings and populations and there is evidence that ACP increases compliance with patients' end-of-life wishes and satisfaction with palliative care (11). In elderly patients, ACP has been shown to improve the quality of palliative care and patients' and families' satisfaction (12). A recent systematic review among nursing-home residents showed that ACP had beneficial effects in this population and led to more actions consistent with residents' wishes and a reduction in unwanted medical interventions at the end of life (13).

The ACP framework and the way in which ACP highlights the wishes and preferences of patients may also be applicable and important for people with ID and their relatives. Due to their limited capacity for understanding and communication, people with ID often do not understand their own health condition, can experience difficulty expressing pain and other symptoms and feelings, and have difficulties with medical examinations or interventions. End-of-life decisions should therefore

always be carefully weighed against the benefits for the patient's quality of life. In ACP for people with ID, all stakeholders, including professionals, relatives and the patient if capable, should be involved in a timely discussion about wishes for future care. As ACP is a broad concept, problems with medical examinations and treatment options now and in the future should be part of the discussions, but ACP also encompasses psychological, social and spiritual matters in palliative care. For example, discussions about the place of palliative care (whether people prefer to stay in their own home environment or move to a hospital or nursing home) (14), or what kind of activities a person would still want to do, can also be elements of ACP. It is important that everybody who is involved in the palliative care for a person with ID joins in discussing the possibilities and restrictions with regard to future care. Professionals often find it challenging to initiate the process of ACP (15). In patients with cancer, physicians wrongly avoid ACP discussions because they are afraid such conversations will cause psychological suffering (16). Research in ID care showed that if relatives and professionals were uncertain whether a person with ID could understand the information, they tended to withhold potentially upsetting news to spare the individual from distress (17). Moreover, a retrospective study of the medical files of people who died in a Dutch healthcare centre showed that patients with ID were not actively involved in any of the end-of-life decisions (18). However, research also shows that most individuals with mild or moderate ID want to be involved. Moreover, they are able to express their views on end-of-life care provision, understand treatment information and make treatment choices, although that ability decreases with the increasing complexity of decision-making regarding care (19-21).

## **Objectives**

Because of the limitations of people with ID in understanding and communicating information, the growing number of people with ID in need of palliative care, and the importance of advance planning in making sure that palliative care is in accordance with a persons' wishes, we want to gain more insight into what is known about the use and effects of ACP in palliative care for people with ID. The questions addressed in this systematic literature review are:

1. What is known about the use and content of ACP or elements of ACP in palliative care for people with ID?
2. Is there evidence that ACP leads to (a) a higher quality of palliative care and (b) a higher quality of life for people with ID?
3. When is ACP initiated and what are the conducive and obstructing factors when introducing ACP in palliative care for people with ID?

## **METHODS**

### **Design**

A stepwise procedure was used to identify relevant papers based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement (PRISMA, see Figure 1) (22). In the first step, all the titles and abstracts of the references identified in the searches were read and an assessment made as to whether they appeared to meet the inclusion or exclusion criteria (see Box 1). In a second step, the first two authors (HV, AV) read the full texts of all the references that potentially

met the inclusion criteria to see whether they indeed met the inclusion criteria. The inclusion process was carried out by the two researchers independently (HV, AV). Disagreements were resolved through discussion or, if there were still doubts, by consulting a third researcher (AdV).

The methodological quality of the studies was graded using a critical appraisal tool (23). This tool was chosen because it was specifically developed to assess multiple kinds of study designs. It consists of nine items (abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalizability, and implications and usefulness). Each item can be scored on a 4-point scale ranging from very poor (a score of 1) to good (a score of 4). The total scores can range from 9 to 36. Scores of 18 or less were labelled 'poor' methodological quality, from 19 to 27 'moderate' quality and above 27 'good' quality. The methodological assessment of each study was done by two researchers independently (HV and AdV or HV and AV). If the maximum difference in the scores of the two researchers was 5, the methodological quality was the average of the two scores. Disagreement between the two researchers (i.e. a difference of more than 5 points) did not occur. To prevent bias, the methodological assessment of a study was never performed by a researcher who had co-authored that publication. Information was extracted by one researcher (HV) and checked by a second researcher (AdV) using a standardized data extraction form (see Appendix A). The extracted data included study identification, study design and data collection, background information on the people with ID, results of the study, and strengths and limitations of the study design.

### **Data sources**

The following international literature databases were searched: PubMed, PsycINFO, Embase and CINAHL. The NIVEL library and Google Scholar were also used to search for relevant studies meeting the inclusion criteria. The search string presented in Box 2 was used for Pubmed and checked by an experienced librarian. For other databases, the search was based on the string used for Pubmed with adjustments where necessary. The databases were searched in June 2016. No language or period restrictions were applied.

#### Box 1. Inclusion and exclusion criteria

##### Inclusion criteria:

- describes empirical qualitative, quantitative or mixed methods research
- concerns people with ID who receive palliative care and/or their relatives/professionals OR concerns people with ID who died non-acutely (after an identifiable period of illness) and/or their relatives/professionals
- describes the use of ACP or elements of ACP such as physical, psychological, social or spiritual matters in palliative care, AND/OR effects of ACP or elements of ACP on the quality of palliative care/quality of life

##### Exclusion criteria:

- letters, editorials, comments or congress abstracts
- case stories that are not analysed systematically
- literature studies (although their reference lists were studied to identify relevant empirical studies)

#### Box 2. Search string used for Pubmed

("Intellectual Disability"[MeSH Terms] OR (mental\*[tiab] or developmental\*[tiab] OR intellectual\*[tiab] OR cognitive[tiab] OR learning[tiab]) AND (retard\*[tiab] OR disab\*[tiab] OR deficien\*[tiab] OR delay\*[tiab])) AND ("palliative care"[MeSH Terms] OR "hospice and palliative care nursing"[MeSH Terms] OR "terminal care"[MeSH Terms] OR "life support care"[MeSH Terms] OR "hospice care"[MeSH Terms] OR "emergency treatment"[MeSH Terms] OR "resuscitation orders"[MeSH Terms] OR hospice and palliative care nursing[tiab] OR (palliative[tiab] OR terminal[tiab] OR hospice\*[tiab] OR life support\*[tiab] OR end-of-life[tiab] OR emergenc\*[tiab])) AND (care[tiab] OR caring[tiab] OR nurs\*[tiab] OR therapy[tiab] OR sedation[tiab]) OR dying[tiab] OR death[tiab] OR end-of-life[tiab] OR terminally ill[tiab] OR critically ill[tiab] OR do-not-resuscitate order[tiab] OR DNR[tiab] OR resuscitat\*[tiab] OR do-not-hospitalize order[tiab] OR DNH[tiab] OR hospitalize order[tiab] OR euthanasia[tiab] OR assisted suicide[tiab] OR treatment withholding[tiab] OR life sustaining treatment[tiab] OR emergency treatment[tiab] OR limited life\*) AND ("advance care planning"[MeSH Terms] OR "advance directives"[MeSH Terms] OR "patient care planning"[MeSH Terms] OR "living wills"[MeSH Terms] OR (advance\*[tiab] OR medical\*[tiab] OR end-of-life[tiab])) AND (directive\*[tiab] OR care plan[tiab] OR care planning[tiab] OR decision\*[tiab] OR decision-making[tiab]) OR decision-making[tiab] OR supported decision-making[tiab] OR truth telling[tiab] OR disclos\*[tiab] OR living will\*[tiab]) AND hasabstract[text]

## RESULTS

The database search resulted in 538 studies after excluding 141 duplicates. Based on the title and/or abstract, 463 studies were excluded due to meeting exclusion criteria and/or not meeting inclusion criteria. Two studies were added after manually searching Google Scholar. Based on the full text assessment, 14 studies met the inclusion criteria and were included in the systematic review (see Figure 1). Table 1 shows the main characteristics of the studies included in this review. Eleven studies



focused on one perspective: that of professionals, relatives, managers or medical records. Three studies reported on multiple perspectives. Of these, two reported on professionals and relatives (24, 25) and one on professionals, relatives and medical records (26). No studies focused on the perspective of the patient with ID. Most studies focused on one element of ACP; four studies focused on two or more elements. The majority of the studies included made use of retrospective data (n=10). The quality of the studies varied from moderate to good. Table 2 shows the data extracted from the studies.

### **Use and content of ACP**

No studies have been found that focused on the broad concept of ACP or studied an ACP programme within palliative care for people with ID. The most commonly studied element of ACP was decision-making, specifically end-of-life decisions (5 of the 14 studies), decisions about medical interventions (n=1), the place of palliative care (n=1), or decision-making in palliative care (n=1). Studies of decision-making show that in the Netherlands, one or more end-of-life decisions were taken for 57% of patients with ID (18). In a comparable study in Switzerland, a percentage of 54% was found (27). Decisions concerning the withholding of life-prolonging treatment are made more often for patients with ID than for patients with other disabilities (27, 28). In end-of-life decisions regarding medical interventions, professionals and relatives believe quality of life and the prevention of suffering to be most important (29, 30).

Seven studies regarding decision-making reported on the involvement of patients with ID in the decision-making process. The wishes of patients with ID, especially of patients with severe to profound ID, are rarely if ever taken into account in decisions about medical interventions in the Netherlands (18, 29, 31). Regarding decisions about the place of palliative care, 72% of professionals believe that the wishes of the patient with ID should be followed but only 8% stated that the patient's wishes were actually taken into account in the decision (32). Wicki & Hättich (2016) showed that patients with ID were less involved in end-of-life decisions than patients with other disabilities. Nevertheless, the involvement of patients with ID was higher in their study than in other studies: they found that almost 70% of patients with ID were involved somewhat to very strongly in end-of-life decisions (27).

Five studies reported on organizational policies regarding ACP (24, 33-36). Three of the five studies looked at 'do not resuscitate' (DNR) policies, in paediatric nursing homes for children with severe developmental disabilities and complex medical problems (34, 35) and in adult day services (ADS) (36). The other two studies focused on policies regarding medical end-of-life decisions (ELDs) (24, 33). The studies showed that no or only a few facilities for people with ID have policy documents on ACP. Moreover, there was often a lack of communication about these policies to professionals, family and/or residents (33).

Three studies reported on collaboration in palliative care (24, 26, 36). People with ID were less likely than people without ID to have access to specialist palliative care services (26). Moreover, hospice service providers had limited experience with people with ID (24, 36). Other elements of ACP that studies reported on were: communication about advance directives (n=1), the inclusion of family in ACP (n=1), the documentation of wishes for future care (n=1) and the start of ACP (n=1).

### **Effects of ACP**

None of the studies included in this review fitted the description of an effect study measuring the outcomes of an ACP programme or intervention. One study did report on the effects of ACP (26). According to the case reviews in this study, ACP contributed to effective care for the patient's illness and conditions, and professionals acted in accordance with the plans that had been discussed. Moreover, professionals felt more confident after ACP discussions in their dealings with the patient.

### **Start of ACP and conducive and obstructing factors**

One study looked at the start of ACP (26) and two studies reported on the start of decision-making (24, 31). Obstructing factors were mentioned in three studies regarding different elements of ACP (24, 26, 36), and conducive factors were mentioned in two studies (25, 31). Physicians preferred to discuss end-of-life decisions in a stable and calm situation, when emotions were under control and enough time could be spent on a sensible discussion (31). However, this was often not possible because of a late diagnosis of the illness (24). Professionals did not always recognize non-verbal symptoms or saw symptoms as part of the disability (24, 36). Moreover, professionals were not prepared to discuss end-of-life issues with the patient because they believed the patient would not understand and they did not know who had the authority to tell the patient directly (24). Therefore, if ACP occurred, it was often acute as a consequence of problems that had arisen, instead of anticipating possible problems that could appear in the future (26). Regarding conducive factors in ACP, professionals noted the importance of nurturing good relationships with the patient's family (25). Physicians believed that a good working relationship with relatives and other professionals was the most important factor contributing to an effective decision-making process (31).

### **CONCLUSION**

Our first research question focused on the use and content of ACP in palliative care for people with ID. Studies included in this review mostly focused on only one element within the broad concept of ACP, which embraces physical, psychological, social and spiritual matters in palliative care. Decision-making, specifically end-of-life decisions, and organizational policies regarding medical issues were the most commonly studied elements of ACP. Other elements that studies reported on were: collaboration in palliative care, communication about advance directives, the inclusion of family in ACP, the documentation of wishes for future care, and the start of ACP. Therefore, we can conclude that some elements of ACP have been studied, but more research is needed to investigate whether ACP should be used and what this process should look like within palliative care for people with ID. For example, it is still unclear when the process of ACP should be initiated, who should be involved, what the roles and tasks of the people involved should be, and what should be discussed.

The lack of reported evidence means we cannot answer our second research question about the effectiveness of ACP regarding the quality of palliative care and quality of life of people with ID. This is striking because the effects of ACP are well studied in various other patient groups for several types of interventions and programmes (11). Furthermore, a review of ACP programmes in long-term care homes studied whether the programmes took the needs of patients with dementia into account (37). For example, a well-studied ACP programme called 'Let Me Decide' (38) focusing on

understanding treatment options in palliative care was considered dementia-friendly because it could be used for both patients with or without mental capacity, and patients and/or relatives were encouraged to re-evaluate their wishes and preferences when the patient's health status changed (37). Although dementia differs from ID in many respects, it would also be interesting to investigate the needs of people with ID regarding ACP and whether programmes like 'Let Me Decide' could effectively fulfil these needs.

The third research question focused on the start of ACP and conducive and obstructing factors in introducing ACP in palliative care for people with ID. Based on this review, there is no evidence that ACP discussions occur frequently. Where ACP is used, this is often in acute circumstances and only after problems have arisen (24, 26). As studies included in this review indicate, there are no clear organizational policies on ACP, which can cause confusion and uncertainty among professionals, as well as among relatives, about tasks and responsibilities (24, 30). Therefore, professionals should be informed about their role and tasks in discussing end-of-life issues and trained in talking about this with people with ID and/or relatives. In that way, professionals will be better prepared for discussing end-of-life issues with people with ID and/or their relatives and be more comfortable with this (15). Advance planning for future care may be important not only for those who become incurably ill and are in need for palliative care, but also for those who are medically fragile from birth on (25, 34, 35). In these patients, the need for ACP discussions and end-of-life decisions may manifest already from birth and will therefore be mainly influenced by the wishes of relatives. However, the need for ACP is not so easy to detect in people with ID with milder disabilities (26). A recent study in the Netherlands showed that only 44% of ID physicians foresaw the death of patients with ID before the last month of life (39). Multiple signals from different information sources and interactions between the patient, professionals and family are needed to be able to identify people with ID who are in need of palliative care (40). This shows that ACP for people with ID is not a uniform process but will take different forms depending on the degree and complexity of the disability and vulnerability of the person with ID. Professionals should therefore use ACP as a flexible process depending on the needs and preferences of the individual and their relatives. The studies included in this review showed that people with ID are often not involved in decision-making about medical issues. Moreover, no study included in this review used people with ID as participants in the study. As a consequence, not much is known about how people with ID in palliative care can be involved in ACP. Although including people with ID in healthcare research can be challenging (41), studies show that it is important to talk to people with ID about their illness and preferences in the palliative phase (42, 43). This enables clarification about what people with ID find important and how people with ID see their own role in discussions about future care. The same applies to including people with ID in ACP discussions in practice. ACP focuses on person-centred care. Without asking the patients themselves about their views and preferences, it remains uncertain whether their wishes will be respected and whether the care provided will satisfy their needs (20, 42, 43). However, allowances need to be made for the fact that people with ID find it more difficult to understand the concept of death, and self-determination in end-of-life planning is less developed (44).



A strength of this study is that it is the first to provide an overview of the use and content of ACP in palliative care for people with ID. Moreover, most of the studies included in this review are of a good methodological quality (12 out of 14). However, the majority of the studies were retrospective or made use of self-reported data and as a consequence were susceptible to recall bias. A limitation of the review is that we only included articles found in Pubmed, PsycINFO, Embase, and CINAHL. We are aware that there could be more relevant studies that are not included in the databases we searched. Two additional studies were detected by manually searching for relevant references.

In conclusion, there are some indications that ACP in palliative care could be useful for people with ID, but more knowledge is needed about the use and effects of ACP as a broad process. Specifically, there is a lack of knowledge about the views and preferences of people with ID themselves about what is important in end-of-life care planning. As a consequence, it is not clear whether and how ACP should be used within palliative care for people with ID and how to involve their needs and preferences in this process. In future research, it is therefore important to investigate the perspective of the patients with ID and ask them about their experiences with and ideas about ACP. In healthcare practice, professionals should be trained in communicating with people with ID and/or their relatives about end-of-life issues.

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## **APPENDIX, FIGURES AND TABLES**

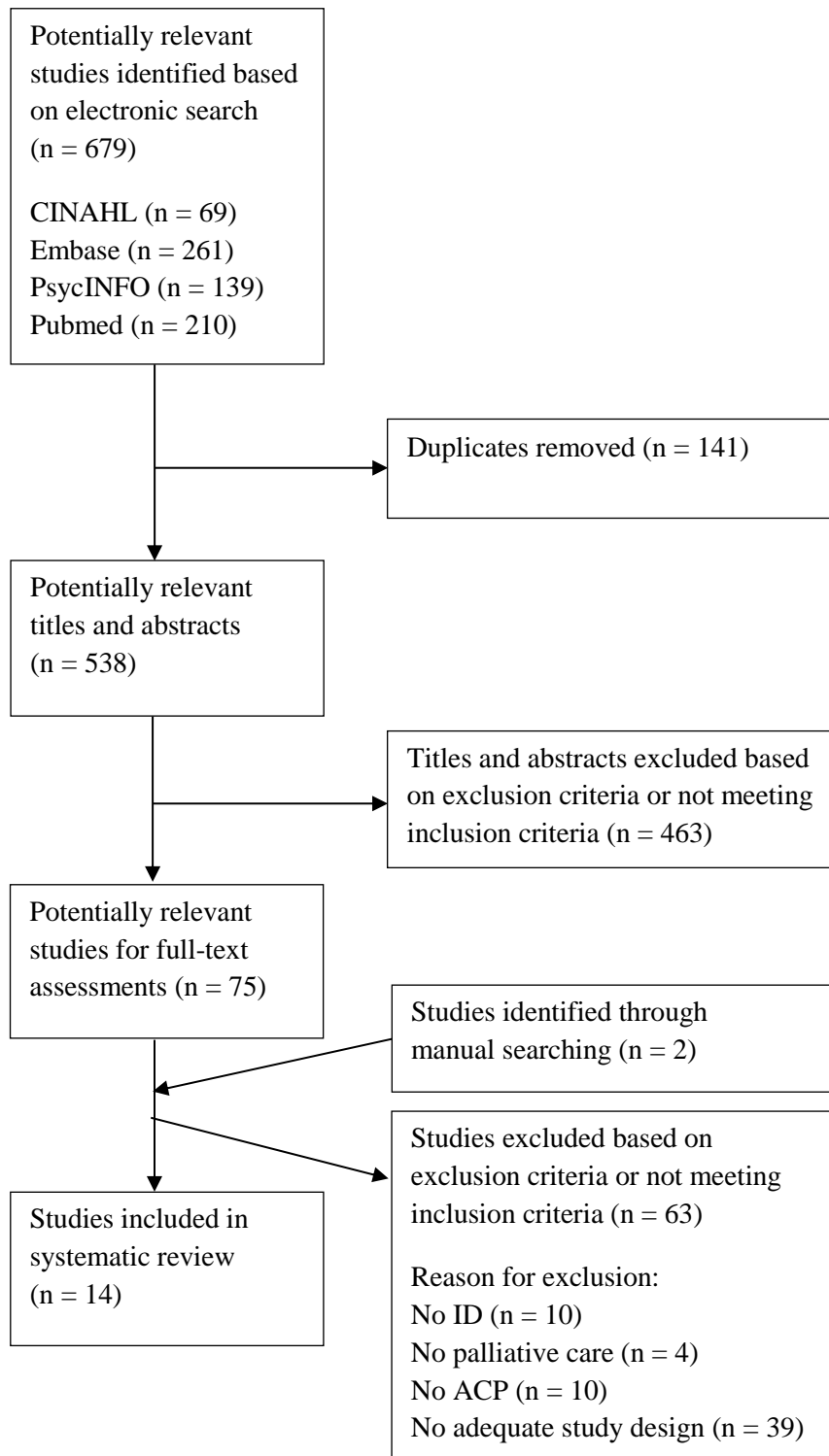
### **APPENDIX A**

#### **Data extraction form**

1. Study ID:
  - Reference: authors/date/title
  - Country
  - Aim and/or research questions
2. Study design and data collection:
  - Quantitative and/or qualitative
  - Total number of participants (n) and response rate
  - Type of analyses
  - Perspective of professionals, patients, relatives, others?
3. Background information of people with ID:
  - Age
  - Severity of disability
  - Medical condition/cause of death
  - Residence
4. Results:
  - Content of ACP
  - Answers to research questions
  - Main conclusion of authors
5. Strengths of study design and limitations
6. Methodological quality

**Figure 1**

*Flow diagram based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (22)*





**Table 2***Extracted data for the studies that were included (n=14)*

1.Study ID	2.Study design and data collection	3.Background information on people with ID	4.Results	5.Strengths of study design and limitations	6.Methodological quality
<ul style="list-style-type: none"> <li>• Reference: authors/date/title</li> <li>• Country</li> <li>• Aim and/or research questions</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative and/or qualitative</li> <li>• Total number of participants (n) and response rate</li> <li>• Type of analyses</li> <li>• Perspective of professionals, patients, relatives, others?</li> </ul>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Severity of disability</li> <li>• Medical condition/cause of death</li> <li>• Residence</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP</li> <li>• Answers to research questions</li> <li>• Main conclusion by authors</li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: three different groups of professionals were incorporated</li> <li>• Limitations:</li> </ul>	Good

<p>with intellectual disabilities: A national survey of the considerations and beliefs of GPs, ID physicians and care staff. (30)</p> <ul style="list-style-type: none"> <li>• The Netherlands</li> <li>• Research questions:</li> </ul> <ol style="list-style-type: none"> <li>1. What considerations do professionals take into account in decision-making about the use of potentially burdensome medical interventions?</li> <li>2. What beliefs do professionals have about the use of potentially burdensome medical interventions in the end-of-</li> </ol>	<p>rate: 46%. 248 ID physicians, GPs and care staff completed questions about the last patient with ID for whom they provided end-of-life care. Considerations in decisions about the use of potentially burdensome medical interventions were described for 140 people with ID.</p> <ul style="list-style-type: none"> <li>• Descriptive analyses</li> <li>• Perspective of professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Causes of death: cancer (37%), overall decline due to old age (17%), dementia (14%), heart failure (6%), stroke (5%), asthma/COPD (2%), other/unknown (19%)</li> <li>• Residence not reported/unknown</li> </ul>	<ul style="list-style-type: none"> <li>- Considerations concerning the quality of life and wellbeing (53%), the wishes of family members (23%) and the wishes of patient with ID (21%) were the most common considerations in decisions about the start or continuation of interventions. The decision to forgo or withdraw an intervention was based on futility of the intervention (38%), quality of life and wellbeing (37%), the direct physical strain on the patient from the intervention (28%), the wishes/preferences of family members (28%), and the direct emotional strain on the patient from the intervention (25%). The wishes of people with</li> </ul>	<ul style="list-style-type: none"> <li>- Questionnaire with multiple choice list which may influenced respondents' answers</li> <li>- Recall bias: respondents may be more likely to recall patients who made a great impact on them</li> <li>- No knowledge about personal input and role of respondent in decision-making process.</li> </ul>
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<p>life care for people with ID?</p>			<p>mild/moderate ID were considered more often (28%) than the wishes of people with severe/profound ID (3%).</p> <ul style="list-style-type: none"><li>- 93% of professionals believe that considerations concerning the quality of life are most important, 72% believe that the patients' possible discomfort outweighs prolongation of life. 70% believe that people with ID should always be informed about intervention options, even when the ability to communicate is limited. Only 43% believe the wishes of the patient with ID should be the deciding factor. If a patient with ID is unable to decide for themselves, 52% of professionals believe that</li></ul>		
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				<p>the opinion of the relatives should be followed, 40% believe the opinion of the physician is decisive.</p> <ul style="list-style-type: none"> <li>• Main conclusion by authors: Professionals believe the quality of life is most important. The wishes of people with ID were often not considered in decision-making about medical interventions.</li> </ul>		
#2	<ul style="list-style-type: none"> <li>• Bekkema, N. et al. (2015). 'To move or not to move': a national survey among professionals on beliefs and considerations about the place of end-of-life care for people with intellectual disabilities.(33)</li> <li>• The Netherlands</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative; pre-structured questionnaires.</li> <li>• 255 care staff and ID physicians responded about the last patient with ID for whom they provided palliative care; response rate for care staff: 67%; rate for ID physicians: 53%.</li> </ul>	<ul style="list-style-type: none"> <li>• Age, severity of disability and medical condition not reported/unknown</li> <li>• Residential setting (56%), community residence (34%), living independently or with family (7%), other/unknown (3%)</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: end of life decisions about the place of palliative care</li> <li>• Answers to research questions: <ul style="list-style-type: none"> <li>- 79% of people with ID received end-of-life care in their own home environment.</li> <li>- Familiarity with the environment (59%), teams' expertise in end-of-</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: broad group of professionals</li> <li>• Limitations: <ul style="list-style-type: none"> <li>- Overrepresentation of people living in a residential residence</li> <li>- Retrospective study</li> </ul> </li> </ul>	Good

<ul style="list-style-type: none"> <li>Aim/research questions: study general beliefs and considerations in decision-making about the best place for end-of-life care</li> </ul> <ol style="list-style-type: none"> <li>To what extent do people with ID move to another care residence to receive end-of-life care?</li> <li>What considerations do professionals take into account when deciding on the place of end-of-life care for people with ID?</li> <li>What beliefs do professionals have with regard to an appropriate environment for end-of-life care for people with ID?</li> </ol>	<p>Considerations underlying decisions about the place of palliative care were described for a total of 237 people with ID.</p> <ul style="list-style-type: none"> <li>Descriptive analyses</li> <li>Perspective of professionals</li> </ul>		<p>life care (45%) and the wishes/preferences of family members (16%) were the most frequently mentioned considerations underlying the decision to provide end-of-life care in the patient's original home environment. The most frequently mentioned considerations underlying the decision to move the patient to another place were teams' lack of expertise (57%), the lack of equipment in the residence (28%) and the unavailability of 24/7 care (17%). The wishes of the patient with ID were mentioned by 8% of professionals as a consideration in whether or not to move the patient.</p>		
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				<p>- 89% of professionals believe that every effort should be made to ensure the patient can stay in their own home environment. 82% believe care should be offered 24/7. 72% believe the wishes of the patient with ID should be the deciding factor, 41% believe this preference outweighs the quality of care that can be given at that place.</p> <ul style="list-style-type: none"><li>• Main conclusion by authors: Despite the belief of professionals that the wishes of the patient with ID should always be given top priority in deciding on the place of care, only 8% of the professionals mentioned that the wishes of the patient were taken into account in this decision.</li></ul>		
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<p>#3</p>	<ul style="list-style-type: none"> <li>• Brown H. et al. (2003). 'Please don't let it happen on my shift!' Supporting staff who are caring for people with learning disabilities who are dying. (24)</li> <li>• UK</li> <li>• Aim: document how agencies mobilized services and made decisions, how agencies worked together and what support staff needed in the patient's last months and weeks.</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative</li> <li>• Interviews with care staff (n = 31), service managers (n = 16), health/learning disability professionals (n = 18), service users (n= 3), family members (n=6), local community representatives (n = 8), and external representative (n = 1) about 21 patients with learning disabilities who had died. Five meetings with staff/team and one with a group of older people with learning disabilities (not reported).</li> <li>• Data were analysed by</li> </ul>	<ul style="list-style-type: none"> <li>• Age range at time of death: 22 – 80 years.</li> <li>• Down syndrome (5), multiple physical and cognitive impairments (2), cerebral palsy (2), mild learning disability (3), moderate learning disability (6), severe learning disability (1), unknown (2)</li> <li>• Causes of death: cancer (n=8), dementia (n=3), respiratory disease/difficulties (n=3), pneumonia (n=2), congenital impairments (n=1), brain tumour (n=1), emphysema (n=1), epilepsy (n=1), unknown (n=1)</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: decision-making in palliative care, organizational policies, collaboration in palliative care</li> <li>• Answers to research questions: <ul style="list-style-type: none"> <li>- Diagnosis of the illness was often late because professionals saw symptoms as part of the learning disability and patients were not able to monitor changes in their own health or express concerns about symptoms.</li> <li>- Services were well supported by primary care teams and by oncology services but less by specialist dementia services. Only one patient had access to a hospice, but the hospice staff were unable to meet his additional</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Strengths and limitations of the study: not mentioned</li> </ul>	<p>Moderate</p>
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		<p>making a graph of the trajectory of illness and key transition points and a network map showing the involvement of various agencies for each patient separately</p> <ul style="list-style-type: none"> <li>• Perspective of professionals and relatives</li> </ul>	<ul style="list-style-type: none"> <li>• Different community-based services (e.g. private residential home, staffed housing service, long-stay hospital and community learning disability service).</li> </ul>	<p>needs.</p> <ul style="list-style-type: none"> <li>- There were no formal protocols in hospitals on care for people with learning disabilities. There was no agreed format for decision-making in any of the cases.</li> <li>- Professionals report confusion about who should be involved in decision-making and especially about the role of relatives.</li> <li>- Decision-making issues were most acute at the point where a shift of treatment goals was most explicit.</li> <li>- Only in the case of one patient were professionals open to the patient about his impending death.</li> <li>• Main conclusion by authors: Professionals were not prepared for disclosure to the patient about their</li> </ul>		
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				impending death because they had the notion that the patient would not understand and they did not know who had the authority to tell the patient directly.		
#4	<ul style="list-style-type: none"> <li>• D'Haene, I. et al. (2010). End-of-life care policies in Flemish residential care facilities accommodating persons with intellectual disabilities. (34)</li> <li>• Belgium</li> <li>• Aim: describe presence, content and implementation strategies of written policies on medical end-of-life decisions (ELDs)</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative and qualitative study</li> <li>• 1. Postal survey among directors of residential care facilities (n = 84, response rate 60%). Descriptive analyses.</li> <li>• 2. Systematic content analysis of policy documents (from 25 institutions). Two researchers performed the analysis independently.</li> <li>• Perspective: other,</li> </ul>	<ul style="list-style-type: none"> <li>• Age not reported/unknown</li> <li>• Occupational type and nursing type (high care needs) for residents</li> <li>• Residence: all residential care facilities (RCF) for people with ID, no selection for type of facility.</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: organizational policies</li> <li>• Answers to research questions: <ul style="list-style-type: none"> <li>- 35% of the institutions have a policy on ELD</li> <li>- Policy documents contained statements about the policy on one or more end-of-life decisions, bereavement care, communication with the family, special needs of people with ID.</li> <li>- Communication of ELD policies to professionals was standard practice in 67-88% of the institutions.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: not mentioned</li> <li>• Limitations: <ul style="list-style-type: none"> <li>- Self-reported data: potentially recall and social desirability bias.</li> <li>- Multiple disabilities of people with ID in RCF unknown: hard to generalize.</li> </ul> </li> </ul>	Good

		management		<p>Communication of ELD policies to residents and families varied between being standard practice (37-56%) and occurring on request (39%-62%) in institutions.</p> <ul style="list-style-type: none"> <li>• Main conclusion: End of life care policies are often not present in Flemish RCFs and are not specifically designed for people with ID.</li> </ul>		
#5	<ul style="list-style-type: none"> <li>• Friedman, S. L. (2006). Parent resuscitation preferences for young people with severe developmental disabilities. (35)</li> <li>• USA</li> <li>• Aim: Assess the effects of providing information</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative; effect study, chart review, before and after intervention. The intervention consisted of written information for parents about resuscitation policy in the case of cardiopulmonary arrest. Parents requesting</li> </ul>	<ul style="list-style-type: none"> <li>• Age: 1 to 32 years (mean 21)</li> <li>• Residence: A paediatric nursing home for children with severe developmental disabilities and complex medical problems requiring 24-hour skilled nursing care.</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: organizational policies</li> <li>• Answers to research questions: The preference for do not resuscitate (DNR) increased from 18% to 43%. There were no parents who wished to change their child's status from DNR to resuscitation.</li> <li>• Main conclusion by authors:</li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: not mentioned</li> <li>• Limitations: <ul style="list-style-type: none"> <li>- Small population</li> <li>- Variables that impact outcome were not available (quality of life)</li> <li>- Data were collected retrospectively via chart review; issues in accuracy</li> </ul> </li> </ul>	Good



	<p>regarding resuscitation to parents and/or guardians of children with severe developmental disabilities on DNR status</p>	<p>resuscitation returned a form that specified their wishes. The other parents were contacted by phone and an appointment was made with the child's physician.</p> <ul style="list-style-type: none"> <li>• Charts of 60 patients were reviewed. After two years, all parents responded (response rate 100%)</li> <li>• Descriptive, univariate and multivariate analyses</li> <li>• 'Other' perspective: medical records</li> </ul>		<p>Provision of information about resuscitation resulted in a significant increase in those who chose DNR rather than full resuscitation.</p>	<p>and detail of information</p> <ul style="list-style-type: none"> <li>- Relatively old data; social and political climate could be different regarding end-of-life considerations</li> <li>- No generalizability to children who reside in their own home or children with other chronic medical conditions</li> </ul>	
#6	<ul style="list-style-type: none"> <li>• Friedman, S. L. &amp; Gilmore, D. (2007). Factors that impact resuscitation preferences for young</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative; pre-structured questionnaire. The survey was part of the implementation of a so-</li> </ul>	<ul style="list-style-type: none"> <li>• Age: 2 to 36 years (mean 19)</li> <li>• Residence: A paediatric nursing home that provides</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: organizational policies</li> <li>• Answers to research questions: Provision of explanatory information</li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: not mentioned</li> <li>• Limitations: <ul style="list-style-type: none"> <li>- Survey sample did not reflect population of</li> </ul> </li> </ul>	Good

<p>people with severe developmental disabilities. (36)</p> <ul style="list-style-type: none"> <li>• USA</li> <li>• Aim: to identify factors that influence parents' and guardians' resuscitation decisions</li> </ul>	<p>called Comfort Care programme for residents with a DNR order.</p> <ul style="list-style-type: none"> <li>• 30 parents/guardians (Response rate 46%)</li> <li>• Descriptive analysis</li> <li>• Perspective of relatives</li> </ul>	<p>care for young people with severe developmental disabilities and complex medical problems requiring 24-hour skilled nursing care.</p>	<p>about resuscitation resulted in a significant increase in those who chose DNR rather than full resuscitation. There were no parents who wished to change their child's status from DNR to resuscitation. Perceptions of the quality of life and medical condition of patient with ID were not significantly different between groups who chose resuscitation and those with a preference for DNR. Parents who chose resuscitation were more influenced by family members (29%), religious leaders (22%) and discussions with the physician (44%) compared to those with a preference for DNR (resp. 0%, 0% and 11%). Parents who opted for DNR were less likely to discuss comfort management with the</p>	<p>facility and findings cannot be generalized to other groups of individuals</p> <ul style="list-style-type: none"> <li>- Small number of participants</li> <li>- No use of standardized measures of quality of life</li> <li>- Other potential contributing factors (parental emotional health and marital relationships) not evaluated.</li> </ul>	
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				<p>physician at the end of life.</p> <ul style="list-style-type: none"> <li>Main conclusion by authors: Parents changed their resuscitation preference to DNR after explanations were provided. Interpersonal relationships were more influential for parents who chose full resuscitation.</li> </ul>		
#7	<ul style="list-style-type: none"> <li>Grossberg, R. I. et al. (2013). Direct care staff and parents/legal guardians' perspective on end-of-life care in a long-term care facility for medically fragile and intellectually disabled pediatric and young adult residents. (25)</li> <li>USA</li> <li>Aim: determine the impact of residents' end-of-life</li> </ul>	<ul style="list-style-type: none"> <li>Quantitative and qualitative;</li> <li>1. Questionnaires about end-of-life experience; 11 bereaved parents/guardians (response rate: 23%) and 18 care staff members who cared for the resident for at least 5 days during the last 30 days prior to death (response rate: 29%) responded. Descriptive analyses.</li> <li>2. Thematic analysis by two</li> </ul>	<ul style="list-style-type: none"> <li>Age: 10-29 years at death</li> <li>Cause of death included respiratory failure/pneumonia, sepsis, intractable seizures, and complications in the underlying disease state/syndrome</li> <li>Residence: A specialized long-term care facility for children and young adults with neurologic</li> </ul>	<ul style="list-style-type: none"> <li>Content of ACP: communication around advance directives, inclusion of family</li> <li>Answers to research questions: <ul style="list-style-type: none"> <li>Parents gave the highest ratings (mean of 4.6 with 1 being very dissatisfied and 5 very satisfied) for doctor's attention to patients' description of symptoms, nursing availability, and family inclusion in treatment and care decisions.</li> <li>Care staff gave the highest rating</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Strengths: not mentioned</li> <li>Limitations: <ul style="list-style-type: none"> <li>Low response rates</li> <li>Retrospective nature (recall bias)</li> <li>Nature of a survey study</li> </ul> </li> </ul>	Good

	<p>experience on their primary care staff members and their parents/guardians</p>	<p>independent statisticians of additional comments on the perspectives of end-of-life care survey.</p> <ul style="list-style-type: none"> <li>Perspective of professionals and relatives</li> </ul>	<p>impairments and severe to profound intellectual disability who are considered medically fragile</p>	<p>for nursing availability (mean 4.2). Parents were more satisfied (median 4.2) with the care provided in the palliative phase than were care staff (median 3.8)</p> <ul style="list-style-type: none"> <li>Parents reported good communication around advanced directives</li> <li>Care staff noted the importance of nurturing relationships with the resident's family</li> <li>Main conclusion by authors: Overall satisfaction with the care provided by parents and care staff. Both parents and care staff felt the patients' needs in terms of pain control, respect and decision-making by parents were adequately met.</li> </ul>		
#8	<ul style="list-style-type: none"> <li>Heslop, P. et al. (2013).</li> </ul>	<ul style="list-style-type: none"> <li>Quantitative and</li> </ul>	<ul style="list-style-type: none"> <li>The median age at death</li> </ul>	<ul style="list-style-type: none"> <li>Content of ACP: documentation of</li> </ul>	<ul style="list-style-type: none"> <li>Strengths and limitations</li> </ul>	Good

<p>Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final Report. (26)</p> <ul style="list-style-type: none"> <li>• UK</li> <li>• Aim: to review the patterns of care that people received in the period leading up to their deaths, to identify errors or omissions contributing to these deaths, to illustrate evidence of good practice, and to provide improved evidence on avoiding premature death.</li> </ul>	<p>qualitative;</p> <ol style="list-style-type: none"> <li>1. Retrospective study of the deaths of 247 people with learning disabilities in 2010–2012</li> <li>2. Interviews with professionals, family members (response rate 34%) and friends and panel meetings with everyone involved in supporting the person</li> </ol> <ul style="list-style-type: none"> <li>• Medical records, perspective of professionals and relatives</li> </ul>	<p>was 65 for men and 63 for women</p> <ul style="list-style-type: none"> <li>• 40% had mild, 31% moderate, 21% severe, and 8% profound and multiple learning disabilities</li> <li>• Frequent causes of death were disorders relating to the heart and circulatory disorders (22%) and cancer (20%).</li> <li>• Residence: residential home (46%), nursing home (18%), housing provider (13%), parental home (13%), own home (8%), other private residence (2%)</li> </ul>	<p>wishes for future care, start of ACP, collaboration in palliative care</p> <ul style="list-style-type: none"> <li>• Answers to research questions</li> <li>- End-of-life care planning took place for two-fifths (43%) of people with learning disabilities. Mostly in the form of a ‘When I die’ booklet that documented a person’s preferences for palliative care. A ‘Child and Family Wishes Advance Care Plan’ had been used for some children.</li> <li>- There was evidence that ACP contributed to effective care and that professionals acted according to the plans. After ACP discussions, professionals felt more confident.</li> </ul>	<p>of the study design: not mentioned</p>
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				<ul style="list-style-type: none"><li>- Planning often appeared to be responsive to problems that arose, rather than anticipating problems that could arise in the future. Unplanned end-of-life care increased the risk for not having a 'good death'.</li><li>- 20% had received support from a specialist palliative care team, 10% from a hospice, and 6 persons had died in a hospice.</li><li>• Main conclusion by authors:</li><li>- Inattention to predicting potential problems, recognizing changing needs and adjusting the provision of care as needs changed made people with learning disabilities particularly vulnerable to premature death.</li></ul>		
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				<p>People with learning disabilities were less likely than the comparator group of people without learning disabilities to have access to specialist palliative care services.</p>		
#9	<ul style="list-style-type: none"> <li>Ronneberg C. R. et al. (2015). Promoting collaboration between hospice and palliative care providers and adult day services (ADS) for individuals with intellectual and developmental disabilities. (37)</li> <li>USA</li> <li>Aims: <ul style="list-style-type: none"> <li>Determine whether collaborations exist</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Quantitative and qualitative</li> <li>1. Two online surveys: One for ADS providers with 103 respondents (response rate: 15%) and one for hospice/palliative care providers with 87 respondents (response rate: 0.05%).</li> <li>2. Four focus groups, two with 10 ADS professionals, and two with 7 hospice/palliative care</li> </ul>	<ul style="list-style-type: none"> <li>Age, severity of disability, and medical condition of people with ID not reported/unknown</li> <li>Residence: hospices and adult day services (48% of ADS with patients with acquired/developmental disabilities as primary population) across the USA and organized in an umbrella organisation.</li> </ul>	<ul style="list-style-type: none"> <li>Content of ACP: collaboration in palliative care, organizational policies</li> <li>Answer to research questions: <ul style="list-style-type: none"> <li>86% of ADS providers were very or somewhat familiar with hospices. 74% of hospice providers reported being very or somewhat familiar with ADS. 55% of ADS providers had an ongoing relationship with one or more hospice programmes. 36% of hospice providers reported</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Strengths: not mentioned</li> <li>Limitations: <ul style="list-style-type: none"> <li>Small sample size and limited by including only organizations that were members of NADSA, Easter Seals and NHPCO.</li> <li>Nonprobability sampling</li> <li>Self-selection of sample</li> <li>Grounded study approach</li> </ul> </li> </ul>	Moderate

<p>between ADS and hospice/palliative care organizations</p> <ul style="list-style-type: none"> <li>- Explore existing barriers to collaboration</li> </ul>	<p>providers.</p> <ul style="list-style-type: none"> <li>• Perspective of professionals</li> </ul>		<p>engagement in activities with one or more ADS programmes.</p> <p>Familiarity with hospices among the ADS providers in the focus group varied widely. To some extent, end-of-life programming takes place in ADS programmes: bereavement and memorial services were provided for staff, patients and their families. Almost half of the hospice and palliative care providers in the focus group referred their patients to ADS.</p> <ul style="list-style-type: none"> <li>- ADS providers in the focus group noted a lack of clear DNR policies within ADS centres. Recognition of nonverbal symptoms of pain was a challenge in ADS centres.</li> </ul> <p>Hospice service providers reported</p>		
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				<p>limited experience with people with ID.</p> <ul style="list-style-type: none"> <li>• Main conclusion by authors: A small number of patients are receiving dual services (hospice and ADS). Both services recognize the potential benefits of collaboration: increasing choice, improving quality of care and quality of life for patients</li> </ul>		
#10	<ul style="list-style-type: none"> <li>• Wagemans A., et al (2010). End-of-life decisions: an important theme in the care for people with intellectual disabilities. (27)</li> <li>• The Netherlands</li> <li>• Aim: investigate prevalence and nature of end-of-life decisions in a residential care centre</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative; retrospective study of medical files of people who died between January 2002 and July 2007 (n = 47), systematically reviewed using a checklist</li> <li>• ‘Other’ perspective: medical records</li> </ul>	<ul style="list-style-type: none"> <li>• 19 residents died in their fifties</li> <li>• Severity of disability: mild to profound</li> <li>• Causes of death: pneumonia (n=9), exhaustion (n=6), heart failure (n=3), peritonitis (n=3), epileptic seizure (n=2), cerebrovascular accident</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: end-of-life decisions</li> <li>• Answer to research questions: <ul style="list-style-type: none"> <li>- One or more end-of-life decisions (withholding nasal feeding tube, withholding therapy, DNR, pain relief/symptom control, second opinion) were made in 27 out of 47 cases</li> <li>- The family was involved in half of</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: not mentioned</li> <li>• Limitations; <ul style="list-style-type: none"> <li>- Only one service included (small sample and not representative)</li> <li>- Retrospective study</li> </ul> </li> </ul>	Good

			<p>(CVA, n=2), choking (n=1), unknown (n=21)</p> <ul style="list-style-type: none"> <li>• Residence: Dutch residential care facility providing care to 335 children and adults with ID living in wards or group homes of 4 to 12 patients</li> </ul>	<p>the cases; nurses were involved in all of the cases. Parents, if involved, had a very important voice in taking end-of-life decisions</p> <p>- No information was noted in the files about the views of the residents themselves or about their capacity to take an end-of-life decision.</p> <ul style="list-style-type: none"> <li>• Main conclusion by authors: Medical end-of-life decisions were made for significant numbers of people with ID</li> </ul>		
#11	<ul style="list-style-type: none"> <li>• Wagemans A. et al. (2013). End-of-life decisions for people with intellectual disabilities, an interview study with patient</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative study based on semi-structured interviews with patient representatives about deceased patients with ID who died in the</li> </ul>	<ul style="list-style-type: none"> <li>• Age range: 40 – 78 years</li> <li>• Mild ID (n=4), moderate ID (n=1), severe ID (n=3), profound ID (n=2)</li> <li>• Causes of death: cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: end-of-life decisions</li> <li>• Answers to research questions: <ul style="list-style-type: none"> <li>- The patient representatives felt highly responsible for the end-of-</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: not mentioned</li> <li>• Limitation: only included deceased patients whom the patient representatives had known intimately</li> </ul>	Good

<p>representatives. (31)</p> <ul style="list-style-type: none"> <li>• The Netherlands</li> <li>• Aim: investigate the role and influence of patient representatives in the process of making end-of-life decisions</li> </ul>	<p>past year (n = 10). The interviews were analysed following the procedures of Grounded Theory.</p> <ul style="list-style-type: none"> <li>• Perspective of relatives</li> </ul>	<p>(n=3), feeding problems (n=2), cognitive or neurological decline (n=2), Parkinson's disease(n=1), COPD (n=1), dementia (n=1)</p> <ul style="list-style-type: none"> <li>• Different residential facilities for people with ID</li> </ul>	<p>life decisions and were passionately involved with the patient.</p> <ul style="list-style-type: none"> <li>- The patient representatives were not sure about the boundaries and limitations of deciding for someone else. They were also not sure about the relevant legislation.</li> <li>- Patient representatives were unsure if patients with ID were able to make choices by themselves and could understand the burden of interventions.</li> <li>- Apart from the doctors, no other professional care providers, such as nurses, social workers or priests, were involved in the decision-making process.</li> <li>- Quality of life and prevention from</li> </ul>	<p>throughout their lives.</p>
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				<p>(further) suffering were the most important considerations in the decision-making process.</p> <ul style="list-style-type: none"> <li>- Support from doctors was important for the representatives. Patient representatives were unaware that doctors are ultimately responsible for end-of-life decisions</li> <li>• Main conclusion by authors: According to patient representatives, the process of end-of-life decision making can be improved by ensuring clear roles and an explicit description of the tasks and responsibilities of all participants.</li> </ul>		
#12	<ul style="list-style-type: none"> <li>• Wagemans A. et al. (2013). The factors affecting end-of-life decision-making by</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative study</li> <li>• Based on semi-structured interviews with 7 ID</li> </ul>	<ul style="list-style-type: none"> <li>• Age range: 40 – 78 years</li> <li>• Mild ID (n=4), moderate ID (n=1), severe ID (n=3),</li> </ul>	<ul style="list-style-type: none"> <li>• Content of ACP: end-of-life decisions</li> <li>• Answers to research questions:</li> </ul>	<ul style="list-style-type: none"> <li>• Strengths:</li> <li>- ID physicians were open about shortcomings and</li> </ul>	Good

<p>physicians of people with intellectual disabilities in the Netherlands: a qualitative study. (32)</p> <ul style="list-style-type: none"> <li>• The Netherlands</li> <li>• Aim: investigate the process of end-of-life decision-making from the perspective of physicians</li> </ul>	<p>physicians about deceased patients with ID who died in the past year after a process of end-of-life decision-making (n = 10).</p> <ul style="list-style-type: none"> <li>• The interviews were analysed following the procedures of Grounded Theory.</li> <li>• Perspective of professionals</li> </ul>	<p>profound ID (2)</p> <ul style="list-style-type: none"> <li>• Causes of death: cancer (n=3), feeding problems (n=2), cognitive or neurological decline (n=2), Parkinson's disease(n=1), COPD (n=1), dementia (n=1)</li> <li>• Small facilities in the community or on a larger campus for people with ID</li> </ul>	<ul style="list-style-type: none"> <li>- No patients were involved in the decision-making process. According to physicians, patients were unable to understand the consequences of a choice and could not comprehend the process of decision-making.</li> <li>- In all but one case, the physicians followed the wishes of the relatives.</li> <li>- Physicians preferred to discuss end-of-life decisions in a stable and calm situation, when emotions were under control and enough time could be spent on a sensible discussion.</li> <li>- According to physicians, good working relations with relatives and paid care staff was the most</li> </ul>	<p>doubts</p> <ul style="list-style-type: none"> <li>- Representative sample of ID physicians</li> <li>• Limitations: <ul style="list-style-type: none"> <li>- Not representative for GPs or medical specialists</li> <li>- Retrospective study, recall bias</li> </ul> </li> </ul>
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				<p>important contributory factor in ensuring an effective process of decision-making.</p> <ul style="list-style-type: none"> <li>Main conclusion by authors: Physicians gave a lot of weight to the opinions and wishes of relatives in the end-of-life decision process.</li> </ul>		
#13	<ul style="list-style-type: none"> <li>Wicki, M.T. &amp; Hattich, A. (2016). End of life decisions for people with intellectual disability – a Swiss survey. (28)</li> <li>Switzerland</li> <li>Aim: explore the prevalence and nature of end-of-life decisions and whether residents are involved in making these end-of-life decisions.</li> </ul>	<ul style="list-style-type: none"> <li>Quantitative study</li> <li>Based on cross-sectional survey with written questionnaires filled in by 78 directors of residential homes (response rate 58%) about people who died (n =233, 97 patients with ID, 59 patients with ID and another disability, 77 patients without ID but with one or more other</li> </ul>	<ul style="list-style-type: none"> <li>Mean age at death 56.3 years (range 17-98)</li> <li>5.8% had a very low, 5.8% a low, 26.3% a middle, and 57.7% a high degree of disability. The degree of disability was unknown for 4.4%.</li> <li>Causes of death were coronary diseases (30.7%), respiratory diseases (16.1%), and cancer</li> </ul>	<ul style="list-style-type: none"> <li>Content of ACP: end-of-life decisions</li> <li>Answers to research questions: <ul style="list-style-type: none"> <li>End-of-life decisions were made for 164 residents (70.4%). These decisions were made significantly more often for residents with ID (74.4%) than for residents without ID (62.3%).</li> <li>When end-of-life decisions were made, family members were involved in the decision-making</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Strengths: not mentioned</li> <li>Limitations: <ul style="list-style-type: none"> <li>Retrospective design and recall bias</li> <li>End-of-life decisions reported not by physicians but by directors</li> <li>Because of cross-sectional nature, no definite conclusions can be drawn</li> <li>No possibility to analyse further factors that could</li> </ul> </li> </ul>	Good

<p>Research question:</p> <ul style="list-style-type: none"> <li>- Is there a difference in end-of-life decisions and involvement between people with ID and people with other disabilities (sensory, physical and psychosocial)?</li> </ul>	<p>disabilities (sensory, physical, and/or psychological).</p> <ul style="list-style-type: none"> <li>• Descriptive statistics</li> <li>• ‘Other’ perspective: management</li> </ul>	<p>(13.5%). 39.7% died due to other or unknown causes</p> <ul style="list-style-type: none"> <li>• All residential homes for adults with disabilities (6 – 300 people)</li> </ul>	<p>process in 120 out of 164 cases (73.2%). Legal representatives were involved in 142 cases (86.6%). Nurses were involved in 136 cases (82.9%).</p> <ul style="list-style-type: none"> <li>- People with ID were less involved in end-of-life decisions than people with other disabilities. 30.1% of people with ID were not involved at all in end-of-life decisions versus 6.5% of people without ID.</li> <li>- The decision to withhold life-prolonging treatment was more likely to be made if advanced directives were present, if the degree of disability was higher and if residents had an ID.</li> <li>• Main conclusion by authors:</li> </ul>	<p>determine the prevalence of end-of-life decisions (such as health condition and prognosis)</p> <ul style="list-style-type: none"> <li>- Directors described a higher degree of disability for people with ID than for people with other disabilities</li> <li>- Only people living in residential homes included</li> </ul>
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				Decisions concerning withholding life-prolonging treatment are made more often for people with ID than for people with other disabilities, and people with ID are less likely to be involved in these decisions.		
#14	<ul style="list-style-type: none"> <li>Wicki M. T. (2016). Withholding treatment and intellectual disability: second survey on end-of-life decisions in Switzerland. (29)</li> <li>Switzerland</li> <li>Aim: explore the prevalence and nature of end-of-life decisions for people with disabilities.</li> <li>Research question: <ul style="list-style-type: none"> <li>Is there a difference in end-</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Quantitative study</li> <li>Based on cross-sectional survey with written questionnaires. Of 156 residential homes for people with disabilities in the three biggest German-speaking regions (response rate: 76.6%), 43 reported on people who died (n=82, 45 patients with ID, 37 patients without ID)</li> <li>Descriptive statistics</li> </ul>	<ul style="list-style-type: none"> <li>Mean age of death 57.2 years</li> <li>Severity of disability not reported/unknown</li> <li>Causes of death were heart and circulatory diseases (26.7%), respiratory diseases (15.6%), cancer (6.7%), and nervous system diseases (17.8%). 33.3% died due to other or unknown causes.</li> <li>Residential homes for</li> </ul>	<ul style="list-style-type: none"> <li>Content of ACP: end-of-life decisions</li> <li>Answers to research questions: <ul style="list-style-type: none"> <li>An end-of-life decision was made in total for 44 people (53.7%) of whom 28 people with ID (62.2%) and 16 people without ID (43.2%). This difference was not significant.</li> <li>The decision to withhold treatment was made significantly more often for people with ID (28.9%) than for people without ID (8.1%).</li> </ul> </li> <li>Main conclusion by authors:</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: not mentioned</li> <li>Limitations: <ul style="list-style-type: none"> <li>Retrospective design and recall bias</li> <li>End-of-life decisions reported not by physicians but by directors</li> <li>Because of cross-sectional nature, no definite conclusions can be drawn</li> <li>Only people living in residential homes included</li> </ul> </li> </ul>	Good

<p>of-life decisions and involvement between people with intellectual disability and people with other disabilities?</p>	<ul style="list-style-type: none"><li>• ‘Other’ perspective: management</li></ul>	<p>people with disabilities</p>	<p>In this study the prevalence of end-of-life decisions (53.7%) is lower than in the first study (70.4%; Wicki &amp; Hattich, 2016)</p>		
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