Aims To provide an overview of the application of SDM in people with ID in the palliative care phase.

Methods In this scoping review, we systematically searched in the Embase, Medline and PsychINFO databases for studies that evaluated the SDM process in people with ID in the palliative phase.

Results Of 402 titles and abstracts, 14 full studies were included. 10 were empirical studies, 3 were opinion papers and 1 was a legal report. Papers show an increasing focus on the importance of involvement of people with ID themselves, or - if applicable - their loved ones, in making medical decisions around the end of their lives. None of the papers described SDM in the palliative care phase, and no best practices, guidelines or definitions were shown for SDM in the palliative care phase.

Conclusion This study shows that there is no consensus-based model about what SDM regarding people with an ID should look like. General recommendations indicate that we should involve people with an ID more in the decision-making process by providing them an appropriate environment full of support.

Background Advance care planning concepts for adults are not directly applicable to the pediatric setting. The aim of the study was to develop a specific pediatric advance care planning (pACP) intervention using a participatory approach.

Methods Bereaved parents and healthcare professionals selected by purposeful sampling participated in two transdisciplinary workshops. In the first workshop, discussion groups identified key elements of pACP. In the second, participants organized the key elements and visualized the pACP process on a timeline. Results were systematized, translated into a modular program, and sent back to participants for validation.

Results The structured intervention organizes pACP elements in a modular design. First steps include 1) Preparation: building up trustful relationships; 2) Opening discussions: framing the process, making participants’ expectations and aims explicit.

The next modules can be arranged in accordance with participants’ priorities: 3) Focusing on the child: quality of life, wishes and hopes; 4) Medical topics: emergency situations and disease-specific crises discussed in hypothetical scenarios; 5) End of life issues: optional.

Final steps 6) Concluding discussions: validation of written documents (e.g. parental advance directives), discussion on their implementation; 7) Implementation: informing all relevant stakeholders.

Timing (initiation, appropriate intervals, actualization), communication, documentation (emergency and care plans, advance directives, discussion protocols), and age-appropriate participation of children and adolescents are transversal aspects pertaining to the whole process.

Conclusion The developed pACP program exhibits a modular design ensuring a structured step-by-step approach as well as a personalized process aimed at meeting the highly individual needs of the child and the family.