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## Operationalisation of self-determination of persons with profound intellectual and multiple disabilities: A Delphi study

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### ABSTRACT

**Background:** The high support needs of persons with profound intellectual and multiple disabilities hamper their possibilities for self-determination. To support their self-determination understanding of what this means for this group is necessary.

**Method:** A three-round Delphi procedure with international experts was undertaken to operationalise self-determination for persons with profound intellectual and multiple disabilities. The quantitative output of Likert scales guided us in finding consensus or differences in the qualitative data. First round qualitative data were analysed thematically.

**Results:** The analysis revealed four topics: (1) statements regarding the characteristics of the person with profound intellectual and multiple disabilities, (2) statements regarding characteristics of the social environment, (3) statements regarding the concept of self-determination, and (4) statements regarding the definition and operationalisation of concepts.

**Conclusion:** Consensus was found on the assumption that persons with profound intellectual and multiple disabilities can live a self-determined life and on the importance of the interplay between persons with profound intellectual and multiple disabilities and the environment in order to experience self-determination.


### KEYWORDS


Self-determination; profound intellectual and multiple disabilities; Delphi study

The first principle of the United Nations (UN) convention on the Rights of Persons with Disabilities (The United Nations, 2006) urges respect for the inherent dignity and individual autonomy of persons with disabilities including the freedom to make one's own choices. Persons with disabilities should be able to live a self-determined life. Self-determination is linked to various positive outcomes for persons with disabilities (e.g., Wehmeyer et al., 2003) and is described by Schalock and Verdugo (2002) as one of the core dimensions of quality of life. While conceptual rapprochements between different theoretical schools in self-determination have been applied to people with mild intellectual disability (e.g., Frielink et al., 2018; Wehmeyer, 2020), the meaning of self-determination for people with profound intellectual and multiple disabilities across multiple domains of life remains elusive, hampering efforts to operationalise this construct. Therefore, the goal of the current paper is to describe the meaning and operationalisation of self-determination for persons with profound intellectual and multiple disabilities according to experts in this field.

The two most important frameworks that describe self-determination in persons with mild intellectual disability are the causal agency theory of Wehmeyer (1992)

and the self-determination theory of Deci and Ryan (2000). The causal agency theory describes how a person develops the capacity for self-determination. Based on this theory, self-determination is conceptualised as a dispositional characteristic, manifested as acting such as to cause changes to happen (Shogren et al., 2017). In their self-determination theory, Ryan and Deci (2000) state that there are three basic psychological needs that are important in the development of self-determination: competence (sense of efficacy), relatedness (sense of caring relationships), and autonomy (sense of volition). These three basic psychological needs are essential in attaining optimal functioning and growth, social development, personal well-being, and quality of life (Felce & Perry, 1995; Frielink et al., 2018; Lachapelle et al., 2005; Ryan & Deci, 2000; Schalock & Verdugo, 2002). These general frameworks on self-determination cannot be readily applied in case of profound intellectual and multiple disabilities, as these frameworks still await empirical validation for this population. Furthermore, these theories presume a certain degree of intentionality and self-awareness; for example, the introjected motivation as described in the self-determination theory (Ryan & Deci, 2000).

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These cognitive functions cannot be readily assumed in persons with profound intellectual and multiple disabilities (e.g., Bruce & Vargas, 2007; Dhondt et al., 2021). Moreover, it is unclear how these frameworks may be translated in communicative acts that allow meaningful interaction with persons with profound intellectual and multiple disabilities around their self-determination.

Due to the high support needs of persons with profound intellectual and multiple disabilities, they may live a controlled life, experience learned helplessness, and have limited possibilities for self-determination (e.g., Nakken & Vlaskamp, 2007; Nieuwenhuijse et al., 2020). Persons with profound intellectual and multiple disabilities are characterised by profound cognitive disabilities (IQ < 20–25) and profound neuromotor dysfunctions (such as spastic quadriplegia). They often have additional sensory impairments and medical problems (such as seizures, respiratory problems, and/or feeding problems) (Nakken & Vlaskamp, 2007). They communicate on a pre- or protosymbolic level, using muscle tension, body movements, vocalisations, or other subtle signals, which are idiosyncratic and context bound (Hostyn & Maes, 2009). These difficulties may impede communication of needs and wishes (Petry et al., 2007). Due to this combination of complex and profound disabilities, persons with profound intellectual and multiple disabilities often depend on others for most aspects of daily life among the life span (Nakken & Vlaskamp, 2007). It is assumed that persons with profound intellectual and multiple disabilities experience the lowest levels of self-determination compared to persons with mild, moderate, or severe intellectual disabilities (Nota et al., 2007; Wehmeyer et al., 1996). Moreover, the more severe the disability, the less convinced professionals have been found about the importance and benefit of self-determination (Carter et al., 2009; Wehmeyer, 2005). For example, in the study of Petry et al. (2005), most direct support workers and parents of persons with profound intellectual and multiple disabilities mentioned “exerting influence on the environment and making choices” as one of the aspects of quality of life. On the contrary, when asking physicians about the operationalisation of quality of life for persons with profound intellectual and multiple disabilities, self-determination was not named (Nieuwenhuijse et al., 2019). Limited opportunities for persons with disabilities in exercising free will and self-determination may relate to a lower quality of life (Lachapelle et al., 2005; Wehmeyer & Schwartz, 1998). However, Wehmeyer (2005, p. 117) also has stated that “small or large, self-determined actions contribute to one’s quality of life”. However, even though parents and professionals indicated that persons with profound intellectual and multiple disabilities sometimes know very

well what they want and do not want and can make their choices known (Petry et al., 2005), Hanzen et al. (2018) concluded for people with profound intellectual and multiple disabilities to make their will and choice understood, they do so primarily within the familiarity of long-term relationships. Relatives of persons with profound intellectual and multiple disabilities indicated that self-determination is more than “making one’s own choices,” it is also about awareness of being in relationships with others, being effectual, and being autonomous (van Tuyll van Serooskerken et al., 2022).

According to relatives, supporting self-determination in persons with profound intellectual and multiple disabilities is complex, as they are dependent on others for all aspects in life the environment in which also includes being given opportunities to express their needs and achieve a self-determined life (van Tuyll van Serooskerken et al., 2022). In order to support self-determination in persons with profound intellectual and multiple disabilities, it is necessary to have a good understanding of what self-determination means for this group. Existing frameworks for self-determination may provide a starting point but may need to be extended to apply to persons with profound intellectual and multiple disabilities. Skarsaune et al. (2021) argue to rethink self-determination in a way that is inclusive for persons with profound intellectual and multiple disabilities, meaning that embedding self-determination in its proper social setting is given due weight. Self-determination has not previously been operationalised within the group of persons with profound intellectual and multiple disabilities (e.g., Nieuwenhuijse et al., 2020; Petry et al., 2005). A Delphi study was undertaken to provide further direction in operationalising self-determination for people with profound intellectual and multiple disabilities. The Delphi methodology has been previously applied in research on persons with profound intellectual and multiple disabilities (e.g., Petry et al., 2007; Wessels et al., 2022). This study is focused on the discussion and argumentation regarding the operationalisation of self-determination, more than reaching consensus (Adler & Ziglio, 1996; Powell, 2003), therefore this study follows the design of a policy Delphi in which alternative opinions regarding an issue (i.e., operationalising self-determination) are confronted (Linstone & Turnoff, 2002). This iterative multistage process provides the opportunity to transfer opinions by using questionnaires (Powell, 2003).

## Methods

To examine the operationalisation of self-determination for people with profound intellectual and multiple

disabilities according to international scientific experts, a three-round Delphi process was conducted. The Ethics Review Board of Tilburg University provided ethical approval for this study (RP32).

### Recruitment of expert panel

The panel of international experts was recruited by purposeful sampling based on their experience and knowledge (Powell, 2003). Panelists had to have specialised scientific knowledge about persons with profound intellectual and multiple disabilities and to meet the following inclusion criteria: (1) having a doctoral degree with at least five years of experience in research focusing on persons with profound intellectual and multiple disabilities or currently conducting a PhD research on self-determination of persons with profound intellectual and multiple disabilities with at least two years of experience in research, (2) being a member of the Special Interest Research Group (SIRG) profound intellectual and multiple disabilities of the International Association for the Scientific Study of Intellectual and Developmental Disabilities which shows their commitment and involvement in the group of persons with profound intellectual and multiple disabilities, and (3) having good knowledge of written English.

The panel was recruited based on a purposeful sampling technique in the SIRG profound intellectual and multiple disabilities of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). Members were informed about the nature and outline of the study by email and asked for their participation in the Delphi procedure with a maximum of four rounds. If they provided their informed consent, they were asked to provide demographic variables (country of research, years of experience, and topics of interest). Participants were informed about the estimated time to complete the questionnaire, which was 30 min in every round. The anonymity and confidentiality of all panelists was guaranteed.

Twenty-three members of the SIRG profound intellectual and multiple disabilities of IASSIDD were selected and contacted by the first author. In homogeneous respondent groups, 10–15 panelists and a 70% response rate in every round are sufficient to receive a reliable result (Adler & Ziglio, 1996; Sumsion, 1998). In the first round, 23 potential expert panelists were asked to participate in the study. A reminder was sent after two weeks and within one month and 16 experts (70%) completed the questionnaire. For the second round, these 16 experts were asked to participate. Because of the summer break in various countries,

**Table 1.** Demographics of the expert panel participated in the three rounds.

	Round 1, <sup>a</sup> n (%)	Round 2, n (%)	Round 3, n (%)
Total	16	11	10
Continent			
Australia	3 (18.75)	1 (9.09)	1 (10.00)
Europe	10 (62.50)	10 (90.90)	9 (90.00)
Asia	2 (12.50)	0 (0.00)	0 (0.00)
North America	1 (6.25)	0 (0.00)	0 (0.00)
Academic degree			
PhD	13 (75)	8 (73)	8 (80)
PhD student	4 (25)	3 (27)	2 (20)
Years of experience in research in persons with profound intellectual and multiple disabilities			
1–5 years	1 (6)	1 (9)	0 (0)
6–10 years	5 (31)	3 (27)	3 (30)
11–15 years	2 (13)	2 (18)	2 (20)
16–20 years	3 (19)	2 (18)	2 (20)
More than 20	5 (31)	3 (27)	3 (30)

<sup>a</sup>One researcher works in more than one country.

we had to extend the response period of one month to three months. A reminder was sent after six weeks. Eleven (69%) experts filled out the questionnaire. These 11 experts were again asked to participate in the third round of the Delphi procedure. Two weeks after sending the initial invitation for this round, a reminder was sent and 10 experts (91%) completed the questionnaire within six weeks. Detailed information on the demographics of the panelists in the various rounds is provided in Table 1.

### Delphi procedure

#### Round 1: preparatory round

The goal of the first Delphi round was to gain as much information on self-determination in persons with profound intellectual and multiple disabilities as possible. The input for this first questionnaire was based on the literature and models related to self-determination in general and more specific for persons with intellectual disabilities (Deci & Ryan, 2000; Frielink et al., 2018; Schalock & Verdugo, 2002; Wehmeyer, 1992, 1999, 2005; Wehmeyer & Garner, 2003; Wehmeyer et al., 1996), and literature specifically focusing people with profound intellectual and multiple disabilities in which self-determination is described as part of quality of life or participation (Hanzen et al., 2018; Nieuwenhuijse et al., 2020; Petry et al., 2005; Roche et al., 2015; Talman et al., 2019; Wood et al., 2005). Based on this literature, the first two authors (S.N. and M.Z.) compiled a list of 59 concepts linked to self-determination (see Supplementary Material A). In an online questionnaire panelists assessed each of these concepts. They indicated to what extent they thought each concept was desirable (qualitative Likert scale 1 = “definitely desirable,” 2 = “probably desirable,” 3 = “may or may not be desirable,” 4 = “probably undesirable,” and 5 = “definitely

undesirable”) in describing self-determination for persons with profound intellectual and multiple disabilities and to what extent they thought the item was feasible (qualitative Likert scale 1 = “definitely feasible,” 2 = “probably feasible,” 3 = “may or may not be feasible,” 4 = “probably feasible,” and 5 = “definitely feasible”) for persons with profound intellectual and multiple disabilities in order to be a self-determining individual. For every concept, the panelists were invited to add comments, suggest clarification, argue in favour for or against issues, or ask questions. The questionnaire ended by two additional open questions in which the panelists were asked if there are any concepts which have not been listed and which, in their opinion, are relevant in operationalising self-determination in persons with profound intellectual and multiple disabilities and if they had any other comments or remarks regarding this list of items. All potential panelists received an email with information about the background and procedure of the study and a link to the online questionnaire.

### *Round 2: statements about self-determination in persons with profound intellectual and multiple disabilities*

In round two, a questionnaire was designed based on the qualitative input of the first round. The questionnaire used in round 2 started with a summary of the general comments the panelists provided on the last two questions of the first round questionnaire and the possibility to respond to the summary. The main part of the questionnaire consists of 26 statements (see Supplementary Material B) regarding self-determination of persons with profound intellectual and multiple disabilities and an overview of the items to which each statement was linked based on the input of first round. The presented statements encapsulated the overarching remarks in the operationalisation of self-determination in persons with profound intellectual and multiple disabilities. How this list of 26 statements was composed is explained in the analyses section. The panelists were asked to indicate to what extent they agreed with the statement (qualitative Likert scale 1 = “strongly disagree,” 2 = “disagree,” 3 = “neither agree nor disagree,” 4 = “agree,” and 5 = “strongly agree”) and responded to two open-ended questions for every item to argue their agreement with the statement.

The panelists of the first round received an email with a link to the online questionnaire. To promote controlled feedback, the following documents were attached to the email: (1) the list of items that respondents were asked to comment on in the first Delphi round (Table 2), (2) the scores on feasibility and desirability of

every item provided in the first round (Supplementary Material A), and (3) the analyses of the qualitative feedback panelists provided in the first round.

### *Round 3: reappraisal in order to achieve a nuanced image on self-determination or persons with profound intellectual and multiple disabilities*

Round three was very similar to round two. The same 26 statements were provided, this time with the summary of the qualitative and quantitative input from round two in order to provide controlled feedback. The summary is provided in the Supplementary Material C. Again, the panelists were asked to indicate to what extent they agreed with the statement and to answer the open-ended questions. This round was focused on the controlled feedback to obtain more information on the views for and against every statement or find consensus regarding the statements. The panelists who participated in the first and second rounds received an email with a link to the online questionnaire.

### **Data analysis**

In every round, the respondents were asked to provide their feedback by use of Likert scales. In the first round, they were asked to indicate the level of desirability and feasibility, and in the second and third rounds, the level of agreement. The input on the Likert scales was analysed by percentage calculation in SPSS statistics 24 software. Consensus among participants was based on passing the threshold of 70% agreement (Hasson et al., 2000; Keeney et al., 2006). This level of consensus was deemed to be a reasonable gauge of the extent to which insight in self-determination in persons with profound intellectual and multiple disabilities was broadly shared among experts, acknowledging that also among experts there may be dissent. These scores on the Likert scales guided us in finding consensus and differences in the qualitative data in which participants describe the various reasons and rationale for agreeing or disagreeing with the various statements.

A thematic analysis was conducted on the qualitative data of the first round. Bottom-up coding of the data was done by hand independently by two researchers (S.N. and M.Z.). The output of these analyses resulted in the 26 statements that formed the basis of the questionnaire in round two. Based on the qualitative input of the second round, a summary was made for every statement. To substantiate the summaries, quotes from the respondents were used and the quantitative information on the level of agreement was added. These summaries were written by the first author (S.N.) and corrected by the second (M.Z.). If no consensus was

**Table 2 .** Levels of agreement with the various statements in rounds 2 and 3.

	Strongly disagree		Disagree		Neither agree nor disagree		Agree		Strongly agree	
	Round 2 (n = 11)	Round 3 (n = 10)	Round 2 (n = 11)	Round 3 (n = 10)	Round 2 (n = 11)	Round 3 (n = 10)	Round 2 (n = 11)	Round 3 (n = 10)	Round 2 (n = 11)	Round 3 (n = 10)
1.1	18.2	20.0	18.2	10.0	36.4	30.0	18.2	40.0	9.1	
1.2	9.1	10.0		10.0	9.1		27.3	<b>70.0</b>	54.5	10.0
1.3			18.2		9.1		18.2	60.0	54.5	40.0
1.4	18.2	40.0	45.5	40.0	27.3	20.0	9.1			
1.5			9.1	10.0	18.2	10.0	45.5	60.0	27.3	20.0
1.6	27.3	20.0	27.3	30.0	18.2	20.0	9.1	30.0	18.2	
1.7	18.2	20.0	9.1	10.0		20.0	45.5	50.0	27.3	
1.8	9.1	10.0	9.1	20.0		10.0	63.6	60.0	18.2	
2.1							9.1	10.0	<b>90.9</b>	<b>90.0</b>
2.2			9.1		9.1		45.5	<b>70.0</b>	36.4	30.0
2.3							9.1	20.0	<b>90.9</b>	<b>80.0</b>
2.4					27.3	20.0	27.3	50.0	45.5	30.0
2.5								20.0	<b>100.0</b>	<b>80.0</b>
2.6					18.2	10.0	36.4	60.0	45.5	30.0
2.7			9.1				36.4	50.0	54.5	50.0
2.8	27.3	20.0	27.3	<b>70.0</b>	9.1		27.3	10.0	9.1	
3.1			9.1		18.2		18.2	<b>90.0</b>	54.5	10.0
3.2							45.5	50.0	54.5	50.0
3.3			9.1		27.3	30.0	45.5	60.0	18.2	10.0
3.4	27.3		45.5	40.0	18.2	50.0	9.1	10.0		
3.5	9.1		18.2	20.0	45.5	<b>70.0</b>	18.2	10.0	9.1	
4.1	9.1	10.0	9.1		18.2	10.0	18.2	<b>70.0</b>	45.5	10.0
4.2			9.1	10.0	9.1		54.5	60.0	27.3	30.0
4.3				10.0	27.3	10.0	27.3	50.0	45.5	30.0
4.4					9.1	10.0	54.5	50.0	36.4	40.0
4.5			27.3	10.0	27.3	30.0	27.3	50.0	18.2	10.0

found between the researchers, the summaries were discussed until consensus was reached. These summaries formed the basis for round three. The qualitative input provided in round three was added to these summaries by the first author (S.N.) and corrected by the second (M.Z.). If no consensus was found between the researchers, the summaries were discussed until consensus was reached.

## Results

In the first part of the Results section, the areas of consensus based on the responses on the Likert scales will be described. The second part describes results from qualitative analyses of statements by participants on the overall meaning self-determination for persons with profound intellectual and multiple disabilities. The third part describes the results of the thematic analysis of responses on the concrete operationalisation of self-determination.

### Consensus ratings

The Likert ratings of desirability and feasibility per concept in the first preparatory round revealed limited consistency. Only a minority of the items surpassed 70% agreement. Thematic analyses of the qualitative data resulted in 26 statements (Supplementary Material B). These statements formed the basis for the questionnaire in round 2. In Table 2, the levels of

agreement with the various statements of round two and three are provided. In round 2, a 70% agreement was only reached for three statements, all of which related to the characteristics of the social environment. Based on controlled feedback, panelists changed their opinion on certain statements in round three, which increased consensus. Agreement of 70% or above was found for nine statements. The summaries of the input of respondents for every statement after round 2 are found in Supplementary Material C.

### *Self-determination in persons with profound intellectual and multiple disabilities: general remarks*

In the general qualitative input in round 2, the panelists indicated that self-determination is an important life goal for everyone, also for people with profound intellectual and multiple disabilities. In the general remarks on the first questionnaire, several panelists stated that these concepts must be regarded as intrinsic to being human and thus as entitlements. In the second round, this was emphasised by stating that we must believe that every human being has the qualities to live a self-determined life. Presuming potential for self-determination should be taken as axiomatic, rather than requiring observable proof. A respondent stated, "We should presume competence rather than incompetence, because it will probably help inclusion and participation." Individual abilities may exceed the expectations

that people have for the person. “It is important not to lock the person into the representations we may have.” According to the respondents, people close to persons with profound intellectual and multiple disabilities must strive to match their actual level of competence. This interplay between the characteristics of the person with profound intellectual and multiple disabilities and the support of the environment was central in discussing the statements regarding self-determination in persons with profound intellectual and multiple disabilities.

### ***Self-determination in persons with profound intellectual and multiple disabilities: concrete operationalisation***

Thematic analyses of the qualitative data of the first round revealed four topics with various statements related to self-determination of persons with profound intellectual and multiple disabilities: (1) statements regarding the characteristics of the person with profound intellectual and multiple disabilities, (2) statements regarding characteristics of the social environment, (3) statements regarding the concept of self-determination, and (4) statements regarding the definition and operationalisation of concepts. Based on the second and third Delphi rounds, more detailed information on the concrete operationalisation of self-determination in persons with profound intellectual and multiple disabilities was collected. The consensus ratings are based on the results of the third round.

### ***Characteristics of the person with profound intellectual and multiple disabilities***

Three respondent (strongly) disagreed that various concepts related to self-determination are not possible for persons with profound intellectual and multiple disabilities to execute as “for many people with profound intellectual and multiple disabilities these skills may be a long way off but we need to work towards them, to allow the dignity of risk for all” (round 2). One other respondent stated, “If we accept that not all persons with profound intellectual and multiple disabilities are able to live a self-determined life we are implicitly self-limiting” (round 2). In line with this, most respondents (strongly) agreed that we should presume the potential for persons with profound intellectual and multiple disabilities to execute skills related to self-determination, while accepting that “sometimes an individual’s abilities exceed the expectations we may have of him or her” (round 2). However, it is also important that “we should not overstrain a person by always asking for something they will never be able to do” (round 2). The respondents indicated that a balance between expectation and

achievements is necessary. One respondent disagreed because: “it is an issue about proximal zone of development assessment” (round 3). This zone of proximal development refers to the differences between what a person can do without help and what the person can do with guidance and help from a more skilled partner.

This view on proximal development regarding self-determination was also stated by three respondents who neither agreed nor disagreed that various concepts related to self-determination are not possible for persons with profound intellectual and multiple disabilities to execute. They referred in this regard to the heterogeneity of this population. Some individuals with profound intellectual and multiple disabilities may be able to execute these skills; others may learn it in a very long process, while others will never reach that point. In line with this, all respondents in round 3 (strongly) agreed that persons with profound intellectual and multiple disabilities might learn new requisite skills, keeping in mind that “They can learn skills related to self-determination in their own way, but it does not mean they learn to do it as we think it is proper” (round 2). Five respondents (strongly) disagreed that some concepts are not feasible because of the cognitive functioning of the person as “the question is if the skills can also be executed on a basic level, without high cognitive skills” (round 2). Three respondents agreed with this statement, although it “depends on which theoretical background we rely, about the cognitive functioning of people with profound intellectual and multiple disabilities” (round 3). Skills for which a certain degree of development or higher cognitive functions is needed, it is unlikely to be expected from people with profound intellectual and multiple disabilities (e.g., self-evaluation, self-management, and self-efficacy). Simple things on a manageable level such as decisions on which toy they want to play with or what they want to eat or drink are possible to execute for most people with profound intellectual and multiple disabilities.

Related to the importance of the interplay between the individual and the environment on the proximal development was often discussed. All respondents in round 3 (strongly) agreed that persons with profound intellectual and multiple disabilities might learn the skills which are not yet present and pointed to the importance of contextual opportunities: “Contextual opportunities, opportunities to experience and benefit from instruction are powerful drivers of skill learning. Individuals with profound intellectual and multiple disabilities are no exception, even if the room for improvement is on a different scale” (round 3). Most respondents (strongly) agreed ( $n = 8$ ) and two respondents (strongly) disagreed that some skills related to

self-determination may not be attainable for some individuals. Five respondents (strongly) disagreed that some concepts are not feasible because of the cognitive functioning of the person. The rationale for their opinion is comparable.

Self-awareness, self-esteem, and intentionality are often described as precursors of self-determination. Most respondents (strongly) disagreed that the ability of a person to present self-awareness depends on their self-esteem. They indicated that “self-esteem may have some effect, but not a large effect and it cannot be described as a causative variable for performance. It is possible to develop primary self-awareness without any idea of self-esteem” (round 2). Five respondents agreed that acting with intent may not be possible to execute for some persons with profound intellectual and multiple disabilities due to their confines of movement and cognition with this statement and six respondents agreed that although the development of intentionality is described as important, it might not develop in at least some people with profound intellectual and multiple disabilities. It may be possible that not all people with profound intellectual and multiple disabilities acquire full intentionality, although “all people show some goal-directed, pre-intentional and potentially intentional behaviors, in often idiosyncratic ways.” One respondent remarked, “perhaps we have not yet found the way to teach it or to enable the person to demonstrate intentionality” (round 2). In round three, a respondent added: “I think the onus is on us to provide scaffolding and opportunities to maximise the achievement of intentionality, but to recognise that we need to work in individuals’ best interest if they have not (yet) achieved some level of intentionality” (round 3). On both statements, three respondents (strongly) disagreed as intentionality is a “central and unquestionable characteristic of human beings” (round 2).

### *Characteristics of the social environment*

When participants referred to the environment, they always referred to other people. In other words, it is about the social environment rather than the physical surrounding. Nine respondents (strongly) agreed that many of the concepts are important in relation to self-determination and could be feasible for persons with profound intellectual and multiple disabilities. They are only feasible if the caregiver or teacher provides the right environment. For persons with profound intellectual and multiple disabilities, it is unlikely to be self-determined, unless there is an interdependency between them and a facilitator, support system, and/or a tool. In line with this, all respondents in round 3 (strongly)

agreed that it is important that the persons in the environment are sensitive to the behaviour, skills, and preferences of the person with profound intellectual and multiple disabilities. This sensitivity in their behaviour is described as “a fundamental tenet of modern best practice” (round 2). Moreover, all respondents in round 3 (strongly) agreed that it is the task of the persons in the environment to create an optimal situation for persons with profound intellectual and multiple disabilities. The persons in the environment must create opportunities so persons with profound intellectual and multiple disabilities have as much influence as possible and activities need to be scaffolded within the possibilities of the person with profound intellectual and multiple disabilities. A respondent stated, “people, selected for their positive attitude, trained to develop their skills, are the most important part of the environment” (round 2 and slightly adjusted in round 3). One respondent neither agreed nor disagreed that self-determination for persons with profound intellectual and multiple disabilities is unlikely unless there is an interdependency between them and a facilitator, support system, and/or a tool because “it is possible, for example, that a person consciously and without the support of others decides to tear his/her clothes (e.g., because he/she no longer likes them). However, this action is not always comprehensible to others. Therefore, no constructive will or intent is seen behind this action and consequently this type behavior is not considered as an act of self-determination. What I would like to stress is that persons with profound intellectual and multiple disabilities may be able to act more autonomously than commonly thought – it is, however, a question of how motives are assessed and interpreted and whether these motives are (commonly) considered adequate (round 2).” Sensitive and supportive persons in the environment are needed to provide persons with profound intellectual and multiple disabilities opportunities for self-determination; moreover, these persons in the environment must be careful in interpreting the behaviour of persons with profound intellectual and multiple disabilities in order to not underestimate their abilities.

Familiarity is important in the relationship between the person with profound intellectual and multiple disabilities and the environment in order to support self-determination. All respondents in round 3 (strongly) agreed that in order to understand the person with profound intellectual and multiple disabilities, it is important that caregivers are familiar with the persons idiosyncratic responses. Identifying preferences can be difficult. It is described as “a basic attitude for parents and professionals” (round 2) to always try to understand personal wishes and desires. Interpretation would

largely depend on the ascription of others or the reflection of the valuing of others. As one respondent stated “We need to value different people’s perspectives and to develop tools and techniques to support interpretations” (round 3). Assessment of a third party may be needed to decide which interpretation is possible closest to the person’s interpretation. Others can only attempt to approach the wishes and needs of the person with profound intellectual and multiple disabilities which is “a general challenge for staff and parents of persons with profound intellectual and multiple disabilities” (round 2). In this regard, one respondent indicated there is a need to think further in the idea of tacit knowledge of direct support workers. Moreover, most respondents (strongly) disagreed ( $n = 9$ ) that for some concepts, respondents indicated it is difficult to judge, it is feasible from an external point of view. Without verbal language, it is not possible to know how the persons with profound intellectual and multiple disabilities feels or thinks about these topics, as “there are other ways to communicate than verbal” (round 3). “If you know a person’s behavior repertoire and ways of communicating you could be able to see, you do not need verbal language” (round 2). Moreover, “a lot can be deduced by observing behavioral reactions of persons with profound intellectual and multiple disabilities” (round 2) and “familiarity and sensitivity help in interpreting communication without words” (round 3). Familiarity and exchange of tacit knowledge can help persons in the environment to interpret the behaviour of persons with profound intellectual and multiple disabilities and provide them opportunities to live a self-determined life.

As previously explained, the environment is important in the self-determination for persons with profound intellectual and multiple disabilities, although all respondents (strongly) agreed that even in optimal contexts some concepts related to self-determination may be achievable for some, but may be very challenging for others. One respondent indicates: “if the will is there, opportunities can occur and be rich experiences for all involved” (round 2). In round three, a respondent added: “the biggest challenge consist in adapting the task, context and support to each individual with profound intellectual and multiple disabilities” (round 3). Moreover, eight respondents (strongly) agreed that in reality persons with profound intellectual and multiple disabilities are offered few options and decision options are more limited to everyday things. Persons with profound intellectual and multiple disabilities have little knowledge about other options. For many, options are only understood through experiencing them, or through the projection of partners. A respondent

indicated that “supported decision-making is important, but it takes skill and time, which can be in short supply” (round 3). Persons with profound intellectual and multiple disabilities have little knowledge about other options. For many, options are only understood through experiencing them, or through the projection of partners. Two respondents indicated they neither agree nor disagree: “I think people with profound intellectual and multiple disabilities need to have more experiences and then be empowered to make choices that work for them” (round 2). There is a clear agreement that the environment plays an important role in providing opportunities for self-determination in persons with profound intellectual and multiple disabilities. In practice, however, it seems difficult to discover what this optimal context is for every person and it might be a challenge to find this for every person.

### *The concepts of self-determination*

All respondents (strongly) agreed there is an overlap between the concepts related to self-determination. It is not always easy to differentiate between the concepts. “Sometimes the items could be interchangeable, or used in different ways in different languages, cultures and contexts. Even within English, it is questionable whether each term maps on to a concept in a one to one correspondence.” A respondent indicated that “perhaps there is need of a transparent theoretical model on this topic.” Most respondents (strongly) agreed ( $n = 7$ ) that it is part of the phenomenon that some items related to self-determination are marked by their circularity with regard to self-determination because they are seen as a consequence of self-determination or self-determination is a part of the concept.

All respondents (strongly) agreed that some concepts (making choices, making decisions, being seen, experiencing the environment, problem solving) are important or vital for the self-determination of persons with profound intellectual and multiple disabilities. A respondent stated, “Although it is complicated there are certain key indicators of self-determination I believe and this research is helping to identify them” (round 2). It was also indicated that not all items equally strong relate to self-determination: “I think you would put a different weighting on items, even if they were all important to a degree” (round 2). Moreover, one respondent agreed that some items could not be linked to self-determination. Four respondents disagreed and indicated that all items may have a direct or indirect link: “Indirect aspects can contribute to self-determination because they lead to people being given opportunities which would otherwise be restricted” (round 2). Moreover, one respondent agreed that it may be

dangerous to associate some items with self-determination as it may lead to attributions of, for example, intent: “he or she did this on purpose to hurt me,” which result in restrictions being placed on the person. Three respondents disagreed: “we should always strive for the best for an individual with profound intellectual and multiple disabilities. Then, an individual with profound intellectual and multiple disabilities may determine if and in which activity he or she may be involved, but if not, the support worker may support the person in this point.” Five respondents neither agreed nor disagreed; they indicated that they are not sure “whether this constitutes danger, especially if all other aspects of environmental support are positive” (round 3).

### *Definition and operationalisation of concepts*

Most respondents (strongly) agreed and emphasised that as for all humans, absolute independence is unlikely to exist for persons with profound intellectual and multiple disabilities. Interdependence seems more realistic when we speak of independence in persons with profound intellectual and multiple disabilities. “There will always be the necessity of a supportive environment” (round 2). One respondent disagreed and indicated “this is about aspirational processes of hope and dignity for persons with profound intellectual and multiple disabilities” (round 3). One respondent neither agreed nor disagreed and stated “we need to be aspiring towards independence even if some people with profound intellectual and multiple disabilities never achieve it, this is the life journey of dignity” (round 2).

Most respondents (strongly) agreed that some concepts could be viewed as falling along a continuum. One respondent describe it as an “inclusive continuum” (round 2), because “describing progressive levels of mastery of a skill does not mean that one adopts a maturationist or innate position. The role of the environment remains intact” (round 3). One respondent strongly disagreed because “Once again ‘we’ blame the disability so we are not responsible, it is easier for us” (round 2). Moreover, most respondents (strongly) agreed that feasibility is higher for simple and concrete everyday life situations, which can be performed with support from the environment. When tasks are more complex, abstract or individual, feasibility seems less likely. This may not mean that it is not worth aspiring to. A respondent indicated, “This is especially true when support is limited, or not very sensitive or responsive” (round 2).

Most respondents (strongly) agreed ( $n = 4$ ) that the definition of various items was not clear which made it hard to indicate the desirability and feasibility for

persons with profound intellectual and multiple disabilities. Moreover, six respondents (strongly) agreed that various items were too abstract to estimate the desirability and feasibility. Three respondents neither agreed nor disagreed and stated that for most items, there is no problem of abstraction but of conceptual definition and differentiation.

### **Discussion**

This study was needed as existing frameworks for self-determination need to be extended to meet the specific support needs of persons with profound intellectual and multiple disabilities. As self-determination has not previously been operationalised within the group of persons with profound intellectual and multiple disabilities, a Delphi study, following a policy Delphi procedure, was undertaken to provide further direction in operationalising self-determination for people with profound intellectual and multiple disabilities. Although finding consensus was not the main focus of this study, the consensus ratings helped in interpreting the qualitative input. In the second round, only for three statements agreement above 70% was found, increasing to nine statements in the third round. Especially with regard to the statements related to the social environment, increased agreement was found. First, in the three-round Delphi procedure, the respondents unanimously stressed that we must assume that persons with profound intellectual and multiple disabilities are able to live a self-determined life. The respondents in this study did not only find it desirable but also feasible for persons with profound intellectual and multiple disabilities to continue the road as described in the UN convention, for example, regarding the first principle which defines universal respect for one’s own autonomy. Stating it is not possible for persons with profound intellectual and multiple disabilities to experience self-determination may be problematic as this assumption might be based on our normative framework of what self-determination characterises. This is in line with the research of Mietola et al. (2017), and we must recognise the equal worth of persons with profound intellectual and multiple disabilities as humans. There was a clear consensus among the respondents that persons with profound intellectual and multiple disabilities might learn the skills related to self-determination that are not yet present, although this being able to learn these skills was linked to the importance of the interplay between the individual and the environment.

Based on a three-round Delphi procedure, any definition and operationalisation of self-determination

should presume the feasibility for persons with profound intellectual and multiple disabilities to be self-determined, while taking into account that self-determination may need to be held to different standards than for people without profound intellectual and multiple disabilities. According to the respondents, feasibility of aspects related to self-determination is higher for simple and concrete everyday life situations such as choosing between two options for dinner. Some aspects (e.g., self-evaluation, self-management, self-awareness) are not described as feasible because of the person's cognitive functioning or difficulties in presenting intentional behaviour. Previous research indicated that it is difficult for persons with profound intellectual and multiple disabilities to present intentional behaviours and that it is often up to the environment to assign purpose to the person's actions (e.g., Dhondt et al., 2020; Neerinckx et al., 2016). However, this focus on deficits or difficulties was criticised by some other respondents as the focus itself would limit the chances to live a self-determined life. Therefore, respondents indicated that to include the abilities of persons with profound intellectual and multiple disabilities, it would be helpful to view the skills related to self-determination on a continuum. This relates to what was also stated by relatives in the study of van Tuyll van Serooskerken et al. (2022), who clearly stated that self-determination in this group is more that making one's own choices. Panelists remarked that persons with profound intellectual and multiple disabilities are a very heterogeneous group which made it difficult to give a general and reliable response to every individual aspect related to self-determination. Some concepts were found too abstract and definitions regarding the respective concepts in the context of (the support of) persons with profound intellectual and multiple disabilities were missing.

In accordance with the autonomy-supportive environment described in the self-determination theory (Deci & Ryan, 2008) and in line with the study of Hanzen et al. (2018) who stated that participation is only possible in relation with the environment, consensus was found among the respondents that the interplay between the individual and the environment in order to be able for persons with profound intellectual and multiple disabilities to experience self-determination is crucial. The environment must provide opportunities for persons with profound intellectual and multiple disabilities to express their experienced wishes and desires. To provide these opportunities, sensitivity to the persons in the environment and familiarity with the person with profound intellectual and multiple disabilities are described as important

preconditions. Providing these opportunities is also assumed as a very difficult task for the environment and an optimal context does not always lead to achievement of self-determination. Consequently, the chances on self-determination of people with profound intellectual and multiple disabilities in everyday life are often limited. In order to empower persons with profound intellectual and multiple disabilities to live a more self-determined life, the persons in the environment must provide more and more varied experiences based on the level of functioning of the person with profound intellectual and multiple disabilities. This finding underscores the role of the social environment for creating opportunities regarding self-determination, in line with the parents who indicated in the study of Van Tuyll van Serooskerke et al. (2022) not only their important role but also the difficulty of supporting self-determination due to limitations in communication and sensorimotor skills in persons with profound intellectual and multiple disabilities.

Some limitations can be described for this study. First, by using a purposeful sampling procedure, the recruitment of the expert panel was restricted to members of the SIRG profound intellectual and multiple disabilities of IASSIDD. This group turned out to be highly diverse in disciplinary backgrounds, national perspectives, and conceptual frameworks, while also bound by having similar frames and references, for example, with regard to the definition of the target group, which facilitated the discussion. However, still more diverse perspectives might be found beyond this population. Second, as the expert panel consisted of international scientific experts, all communication was in the English language. As not all panelists are native English speakers, it may have been difficult for some to understand questions or to describe their thoughts. However, as all participating experts publish scientific articles in international English language journals, we assume their level of understanding was sufficient for this study. Third, it might be a limitation that the experts in the panel are not as familiar with all theoretical frameworks and concepts related to self-determination.

Self-determination of persons with an intellectual disability is highly prioritised in policy and practice worldwide (The United Nations, 2006). This study provides a contribution to the operationalisation of the concept self-determination for the group of persons with profound intellectual and multiple disabilities. Experts on this group agreed that persons with profound intellectual and multiple disabilities should be presumed to exert self-determination and therefore

are also subject to the right of respect and support for self-determination, even though the operationalisation of the construct needs to be adapted to their abilities and needs. The experts clearly agreed that the self-determination of persons with profound intellectual and multiple disabilities highly depends on the support they receive and that this support is often lacking. Further research is needed to gain insight in the concrete operationalisation of the various concepts and how we can observe self-determination behaviours in persons with profound intellectual and multiple disabilities. This knowledge is highly relevant in creating a supportive environment. Awareness of the opportunities regarding self-determination in the group of persons with profound intellectual and multiple disabilities may lead to different choices in supporting this group, for example, in incorporating the client perspective in the application of restrictive measures or involuntary care. The knowledge built in this study can be incorporated in staff training to help them think about how self-determination can be supported for the group of persons with profound intellectual and multiple disabilities. It might help staff to also give persons with profound intellectual and multiple disabilities the opportunity to live a self-determined life while taking into account their significant support needs. Collaboration with relatives, who bring in intimate knowledge, is likely to be helpful (Van Serooskerke et al., 2022). Moreover, future research is needed on the perspectives of parents and practitioners as this would offer additional valuable insights on this topic as their knowledge is not scientifically based, but more practical and experiential. The insights derived from the present study are much needed as they provide the necessary input to conduct further research on this theme. Further research may investigate how self-determination for persons can be supported, which may inform practice on how to organise a self-determination supportive environment and in order to organise the proper support to provide persons with profound intellectual and multiple disabilities with opportunities to experience self-determination in life.

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