Research in Developmental Disabilities 121 (2022) 104153

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

Development and preliminary validation of the Self-Awareness Situation-Based Observation Lists for children with Profound Intellectual and Multiple Disabilities

Juliane Dind [a,*], Geneviève Petitpierre [b]

[a] Department of Special Needs Education, University of Fribourg, Rue St-Pierre Canisius 21, 1700, Fribourg, Switzerland
[b] Department of Special Needs Education, University of Fribourg, Rue St-Pierre Canisius 21, 1700, Fribourg, Switzerland

ARTICLE INFO

No. of reviews completed is 2

Keywords:
Profound intellectual and multiple disabilities
Ecological self-awareness
Self-Awareness Situation-Based Observation List for children with Profound Intellectual and Multiple Disabilities (SAOL-PIMD)
Reliability
Social validity

ABSTRACT

Background: A primary, pre-reflective form of self-awareness develops during the first two years of life, through sensory perceptions and bodily and social experiences. Although this is a central dimension in the development of children with PIMD, no tools are available to guide caregivers' observations.
Aims: To present the development procedure and the results of the first validation step of a battery aimed at direct observation of primary self-awareness behaviors in children with PIMD.
Methods and procedure: We built a criterion-referenced tool composed of five scales proposed in two complementary lists. The first list comprises inducing standardized tasks; the second natural observation situations. The battery was administered three times to 18 children with PIMD.
Outcomes and results: The inducing tasks list was shown to be reliable, with good internal consistency, inter- and intra-rater reliability, high procedural reliability and high test-retest reliability. The natural observation situations list has a lower internal consistency, but high test-retest reliability. The social validity of both lists is deemed to be excellent.
Conclusion and implications: The tool looks promising. Even if these first results need to be confirmed by further research, it opens up perspectives for assessment and intervention on a key dimension of human functioning.

What this paper adds?

At a conceptual level, our paper underlines the interest of the ecological perspective on primary self-awareness for the understanding of its development in people with PIMD. It also offers methodological perspectives on the construction of direct assessment tools for people with PIMD. The paucity of available specific theoretical frameworks that could lay the foundations for the development of assessment instruments for this target group can be addressed by applying and adapting developmental theories to people with PIMD. Procedural options for dealing with the specific challenges of this group are proposed, among them, the need to accurately and comprehensively describe their complex and subtle behavioral responses, to repeat measurements, and to vary the contexts of observation.

Abbreviation: ESA, Ecological self-awareness.

* Corresponding author at: Département de pédagogie spécialisée, Université de Fribourg, St-Pierre Canisius 21, 1700, Fribourg, Switzerland.
E-mail addresses: juliane.dind@unifr.ch (J. Dind), genevieve.petitpierre@unifr.ch (G. Petitpierre).

https://doi.org/10.1016/j.ridd.2021.104153
Received 26 August 2021; Received in revised form 26 November 2021; Accepted 14 December 2021
Available online 20 December 2021

1. Introduction

Self-awareness is a core dimension of human functioning (Blanke, Slater & Serino, 2015), even “so fundamental to our human experience that we hardly ever think about it” (Kircher & David, 2003b, p. 445). If the question of its origin remained a mystery for a long time, the last three decades have seen the number of researches devoted to this topic explode, with the consequent appearance of new terminologies and new models. At the terminology level, authors use different nonconsensual terms to describe self-awareness (Morin, 2006; Rochat, 2016; Zelazo, 1996). They agree that there are different levels or degrees of self-awareness, but they disagree about which term qualifies the lower/upper order. Butterworth (2000) for example, uses the term "self-consciousness" to designate the higher degree of the ability to become the object of one’s own attention, while Morin (2006) chooses the term "self--awareness" to qualify this same degree. At the epistemological level, perspectives on self-awareness can be very different from one discipline to another (Kircher & David, 2003a), for example philosophy or neurosciences. This multiplicity of perspectives and terminologies makes it difficult to find a consensus in the scientific literature on a definition of self-awareness.

Research in developmental psychology has made an essential contribution to understanding the origins of self-awareness, because it is concerned with how the foundations of self-awareness develop in its early ontogeny. A vast body of scientific studies reports numerous observations of very precocious behaviors in typically developing children, suggesting the existence of a pre-reflective form of self-awareness, developing from birth until the appearance of verbal language, called "primary self-awareness". At 2 years and above, these behaviors are likely to prefigure more complex self-awareness skills (indicators of a superior form of self-awareness), i.e. abilities to talk about oneself (self-descriptive abilities) as well as meta-reflective abilities manifested later in adolescence and adulthood (e.g. being aware that one is self-aware). But primary self-awareness does not disappear in adulthood. Some scholars claim that multisensory study of self-experience should be systematically conserved in cognitive and/or adult models (Faivre, Arzi, Lunghi, & Salomon, 2017), as it remains crucial and active and ensures (bodily) self-consciousness in states of reduced vigilance (Salomon et al., 2017). Phenomenological exploration suggests indeed that self-awareness entails, at least, a sense of stability (“maintenance of a stable milieu”) (Damasio, 1999; Dolan, 1999), a sense of continuity (feeling and/or knowing to be and/or remain the same person across time despite the aging and/or developmental processes) (Kircher & David, 2003b), a sense of agency (feeling and/or knowing to be the author of our thoughts or actions), a sense of localization (experience of the self in space, and/or the space located in relation to oneself) (Blanke & Metzinger, 2009; Ehrsson, 2007; Lenggenhager, Tadi, Metzinger, & Blanke, 2007), and a feeling of self as being distinct from other people and/or the rest of the environment (Kircher & David, 2003b).

The ecological perspective on primary self-awareness has played an essential role in developmental psychology studies on the topic. It has clearly shown that the ecological self-awareness (ESA) of each individual is rooted in numerous and recurrent experiences of self-feeling, generated by the ongoing signals from one’s own body, in particular proprio- and interoceptive signals which have very high self-valence (Kircher & David, 2003a). In other words, primary self-awareness “is based in perception” and “depends on being embodied and situated in a physical and social environment" (Butterworth, 2000, p. 19). Moreover, this perspective has identified that the ESA “is not singular, but multiple; it is dynamic, in constant flux among levels of various experiential qualities all through the life span” (Rochat, 2009, p. 104). Based on empirical research in infants and children, Rochat (2003b), 2012, 2014) proposes an ontogenetic model of ESA, which highlights these dynamic and multidimensional aspects. This heuristic model can be represented as follows (see Fig. 1).

In this model, the differentiated sense of self refers to the baby’s ability to "discriminate between what corresponds to his own body and what corresponds to the body of others or to the body of things that exist independently of oneself" (Rochat, 2010, p. 61). The sense of organized self is defined as the baby’s ability to "perceive his own body as a whole organized according to a particular configuration,

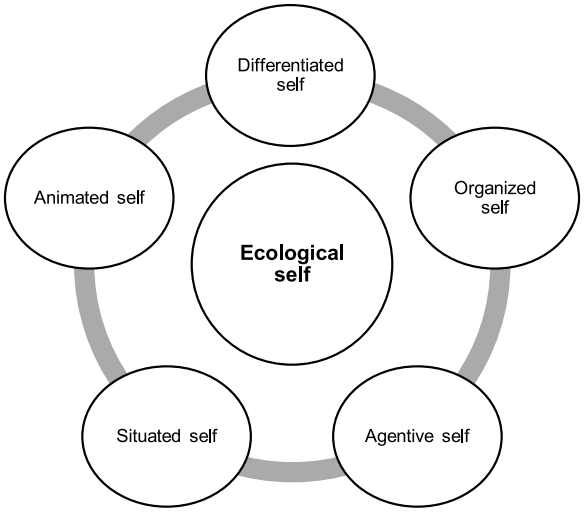

Fig. 1. Rochat’s five-facet model.

not as a collection of disjointed parts" (Rochat, 2006, p. 70), as well as to articulate signals (intermodality) and to link the product of his sensory perceptions (Rochat & Goubet, 2000). The sense of agentive self refers to the baby's ability to "control his environment, to behave as an agent in the environment" (Rochat, 1993, p. 46) and to "instrument his body according to certain perceptual consequences and preferential events" (Rochat & Goubet, 2000, p. 281). The sense of situated self refers to the baby's ability to "situate his body in relation to things around him and to perceive what he can and cannot do in relation to them" (Rochat, 2010, p. 62). Finally, the sense of the animated self refers to the propensity of babies to animate their bodies, to perceptively experience the fluctuating dynamics of the rich and varied emotions that their body is the place of (pleasure, excitement, satisfaction…) (Rochat, 2006).

In contrast to the growth of research on self-awareness in developmental psychology, research in special needs education has so far shown little interest in the development of self-awareness in atypically developing children. Such research would, however, make it possible to highlight mechanisms that cannot be seen in typically developing children (Duff & Flattery, 2014; Hobson, Chidambi, Lee, & Meyer, 2006; Lyons & Fitzgerald, 2013), and thus to better understand the foundations of the development of self-awareness. Among atypically developing children, children with PIMD form a heterogeneous group combining a profound intellectual disability, a profound motor disability and frequent sensory impairments. This vulnerable group of persons has a heavy or total dependence on personal assistance for everyday tasks (Nakken & Vlaskamp, 2007; SIRG-PIMD, 2001). People with PIMD are also at risk of developing various medical complications throughout their life (van Timmeren, van der Putten, van Schrojenstein Lantman-de Valk, van der Schans, & Waninge, 2016). Despite the fact that the improvement of self-awareness abilities is a goal mentioned in several curricula designed for people with PIMD (Brisson, Bujold, & Lemay, 2011; Council for the Curriculum, E. & A., 2007; Curriculum & Qualifications Group, 2006; Petitpierre & Gyger, 2014; Rodi, 2013; South Lanarkshire Council, 2015), very little is known about how these children develop self-awareness. Thus, important questions remain unanswered about how these children perceive themselves, their bodies, and their environment. At the pedagogical level, professionals do not know which behavioral indicators to observe in order to gain access to the self-awareness of these children, outside of the testimony of language. To our knowledge, no primary self-awareness observation tool exists, either for the target group of our research or for children with other deficiencies. However, the indicators of ESA in neurotypical infants provide cues to identify such manifestations in children with PIMD. The aim of our study was therefore to develop a new observation tool based on Rochat's model, the *Self-Awareness Observation List for children with PIMD* (SAOL-PIMD) (2020, Dind, 2018), and to answer our research question: what are the psychometric qualities of the instrument?

2. Method

2.1. Type and purpose of the tool

We decided to develop a criterion-referenced instrument, supporting direct observation of ecological self-awareness indicators and allowing behavioral responses to be coded according to predetermined criteria. Proposing coding criteria is important to reduce the risk of different interpretations of behavior (Vlaskamp & Cuppen-Fonteine, 2007; Vlaskamp, 2005). Direct assessment tools, especially tailored to people with PIMD, are scarce, therefore the need to develop them is important. Such tools are essential for confirming or denying patterns and levels of functioning of people with PIMD, for measuring progression or regression, and for determining the starting point for treatment or support programs (Nakken & Vlaskamp, 2007; Tadema, Vlaskamp, & Ruijssenaars, 2005; Vlaskamp, 2005; Wessels, Paap, & Van der Putten, 2020). Moreover, these tools allow researchers to "attend closely to the person's actual behavior in real life, taking into account the context of the observed behavior, without solely depending on proxies' interpretation "(Maes et al., 2020, p. 5).

The SAOL-PIMD has predominantly been designed for children with PIMD from 4 to 12 years old. It aims to to guide caregivers' observations and possible interventions aimed at supporting the construction of the sense of self of people with PIMD. Given that variation of contexts is essential for the observation of individuals with PIMD (Maes et al., 2020; Petitpierre et al., 2013; Vlaskamp, 2005), our observational battery consists of two distinct lists of items (see Fig. 2): 1) *the SAOL-IT (Inducing Tasks),* where the child is confronted with a standardised task inducing a behavioral response, administered by the experimenter; 2) *the SAOL-NOS* (*Natural Observation Situations*), where the child's behavior is observed by direct support workers (DSWs) in the course of their everyday life.

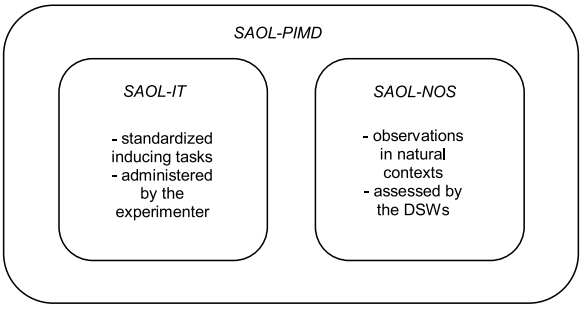

Fig. 2. Composition of the battery.

2.2. Tool development process

We engaged in a multistep process to create a draft version of the battery. Considering the methodological recommendations (Laveault & Grégoire, 2014; Rust & Golombok, 2009), the item production process was carried out in three steps: 1) the content analysis and content extraction of the theoretical model; 2) the item generation process; and 3) the implementation of a pilot study to check the draft version of the tool.

2.2.1. Content analysis and content extraction of the model

ESA is an hypothetical entity that cannot be observed directly. This is why we first had to make an inventory of the relevant operational behaviors corresponding to each of the five facets of Rochat's model (Rust & Golombok, 2009). We carried out this inventory based on Rochat's publications. This step was facilitated by the precision of the definitions and the numerous examples given by Rochat himself in a set of articles and chapters published over a range of 25 years (2003a, 2003b, 2009, 2010, 2011, 2012, 2015a, 2015b, Rochat, 1993, 2016). The summary of this inventory is available in the appendix.

2.2.2. Item generation process

The item generation process is another crucial step in the process of the tool construction, since "the success of a test depends on the success of its items" (Rust & Golombok, 2009, pp. 1190–1192). We first selected three instruments validated and used in the assessment of people with PIMD: (i) *Behavioural Appraisal Scales [BAS] for people with profound intellectual and multiple disabilities* (Vlaskamp, Van der Meulen, & Smrkovsky, 2002); (ii) *Les échelles d'évaluation du développement cognitive précoce [Scales for Assessment of Early Cognitive Development] [ECDCP]* (Uzgiris & Hunt revised by Nader-Grosbois, 2013) and (iii) the French version of the *Scale of Psychomotor Development of Children, also known as the Brunet-Lézine Scale* [B-L Scale] revised version (Josse, 1997). Then we inventoried in these instruments all the items dealing with ESA indicators, according to the content analysis and extraction of the model. 29 items were selected as a result of this procedure. We completed the first draft (version 1.0) by creating 17 items inspired by Rochat's experimental studies with infants. The 46 items (28 items in the *SAOL-IT* and 18 items in the *SAOL-NOS*) were assigned to each of the five scales corresponding to the facets of the model.

In order to verify whether the items corresponded to the assigned dimension, a scientific collaborator in special needs education blindly classified the 46 items into the five scales. The rate of agreement between the two assignments was calculated using the formula: R = (A/A + D) x 100 where R = reliability on agreements, A = number of agreements and D = number of disagreements (Green, Gardner, Canipe, & Reid, 1994; Mudford, Hogg, & Roberts, 1997). An agreement rate of 0.90 was achieved. The procedure allowed some items (n = 3) to be removed, and some to be reassigned to another scale (n = 3). 12 items were also added to the *SAOL-NOS* in order to complete the list. These modifications resulted in a second version of the battery (version 2.0) consisting of 54 items, among which 27 comprised the *SAOL-IT* and 27 the *SAOL-NOS*.

2.2.3. Pilot study

Carrying out a pilot study is an important methodological precaution when creating an assessment instrument for people with PIMD (Maes et al., 2020). We did so in order to check the applicability of the items (practically) and to further specify the handover conditions describing each item. The battery (version 2.0) was administered to 6 children with PIMD who meet the definition of the SIRG-PIMD (2001). The sample consisted of six boys ($M = 8.9$ years, $SD = 3.7$ years). In order to assess the adequacy of the items for all children with PIMD despite their heterogenous motor and sensorial functioning, sample diversity was maximized on motor and sensory functioning criteria. Children presenting both levels IV and V in the Gross Motor Function Classification System - Expanded and Revised (Palisano, Rosenbaum, Bartlett, & Livingston, 2008), as well as children with and without associated visual/auditive impairment were included in the sample. This allowed the main sources of PIMD heterogeneity to be covered and to operationalize the target group's characteristics (Maes et al., 2020).

The *SAOL-IT* was administered to each child individually by the first author in a room well known to the children in their school, in the presence of a DSW. All sessions were filmed. The *SAOL-NOS* was assessed in class by the DSWs. Following the viewing of the videos and feedback from the staff, several modifications were made to improve the tool:

- 10 items (4 in the *SAOL-IT* and 6 in the *SAOL-NOS*) were removed due to the lack of adequacy of these tasks with the participants' motor restrictions.
- 17 items (11 in the *SAOL-IT* and 6 in the *SAOL-NOS)* were created, inspired by the behaviors shown by the participants and by the suggestions of professionals.

Table 1
Structure of the ready-to-validate version of the SAOL-PIMD (3.0).

Source	Differentiated self (n = 9)		Organized self (n = 11)		Agentive self (n = 13)		Situated self (n = 17)		Animated self (n = 11)	
	SAOL-IT	SAOL-NOS	SAOL-IT	SAOL-NOS	SAOL-IT	SAOL-NOS	SAOL-IT	SAOL-NOS	SAOL-IT	SAOL-NOS
Pre-existing tools	1	0	5	4	8	3	8	3	3	3
Experimental studies	3	5	1	1	0	2	2	4	3	2

The ready-to-validate version of the battery (version 3.0) finally included 61 items, among them 34 in the *SAOL-IT* and 27 in the *SAOL-NOS* (see Table 1).

2.3. Tool presentation

2.3.1. Items format

In writing the items, we referred to the format of items used in Uzgiris and Hunt (1980) revised version by Nader-Grosbois (2013). For each item (see Table 2), we drafted a definition of the target skill. We also added detailed information on 1) the positioning of the child and that of the experimenter; 2) the objects or stimuli to use, and the way to present them; 3) the steps in administering the task and 4) the oral instructions to be given to the child, when such instructions were required.

2.3.2. Behavioral indicators

Since the *SAOL-PIMD* is a criterion-referenced instrument, expected behavioral responses indicative of critical behaviors were described for each item, as well as emergent and non-critical behaviors. Defining behavioral indicators of people with PIMD is particularly complex; due to their limited behavioral repertoire, the characteristics of the key responses must be precisely defined (Maes et al., 2020). Fig. 3 depicts the five categories of indicators highlighted by the scientific literature (Logan et al., 2001; Mechling & Bishop, 2011; Neerinckx & Maes, 2015; Squillaci Lanners, 2005):

All the behavioral responses have been operationalized according to these indicators, as illustrated below (see Table 3) regarding intentionality:

2.3.3. Scoring protocol

A three-point scoring system on an ordinal scale was used, depending on the type of behavior displayed: 2 points: manifestation of a critical behavior; 1 point: manifestation of a behavior indicating the emergence of the skill *a*nd 0 points: manifestation of a non-critical behavior. An observation grid with a description of all behaviors corresponding to each score was used. A minimum of two viewings of the video sequences were required to be able to score each item.

2.4. Sample

Four special needs education schools, located in the French-speaking region of Switzerland, agreed to take part in the research. 20 pupils with PIMD were included in the study, but the participation of 2 children was interrupted because of health problems, which is a recurrent challenge in the research on PIMD (Maes et al., 2020). The children's ages ranged from 7 to 12 years ($M = 9.44$, $SD = 1.88$). DSWs provided details about the participants' characteristics by means of a survey (see Table 4). The criteria for inclusion were 1) having PIMD, according to the characteristics described by the SIRG-PIMD (2001) and 2) be aged between 4 and 12 years old. The age range was determined pragmatically, in order to correspond to primary-school age, before the onset of puberty. Ethical approval for the study was obtained from the "Cantonal Commission of the Canton of Vaud on the ethics of research on humans" in June 2014 (Protocol 154/14). Access to classes was approved by the education authorities. Written consent was obtained from the parents.

2.5. Procedure

The following conditions were monitored throughout the administration of the *SAOL-IT*, because of their possible influence on the performance of people with PIMD.

2.5.1. Contextual variables

The inducing tasks were administered by the first author in a quiet dedicated room in the participants' usual school. The assessment took place once a week, in the same time slot in the presence of a DSW.

Table 2
Example of item.

Variable	Informations
Observed skill	Intentional tower demolition
Child positioning	Sitting behind a table or with a tray or lying on their side
Experimenter positioning	Sitting or crouching next to the child
Material	4–5 wood blocks
Task administration	1) Build a tower on the table/tabletop at a distance of about 10 cm from the child's hands (either in the central axis or diagonally to the side). 2) Demonstratively tap the blocks to knock the tower down. 3) Rebuild the tower and give the instructions.
Instructions to the child	*« It's your turn, it's your turn to knock the tower down! »*

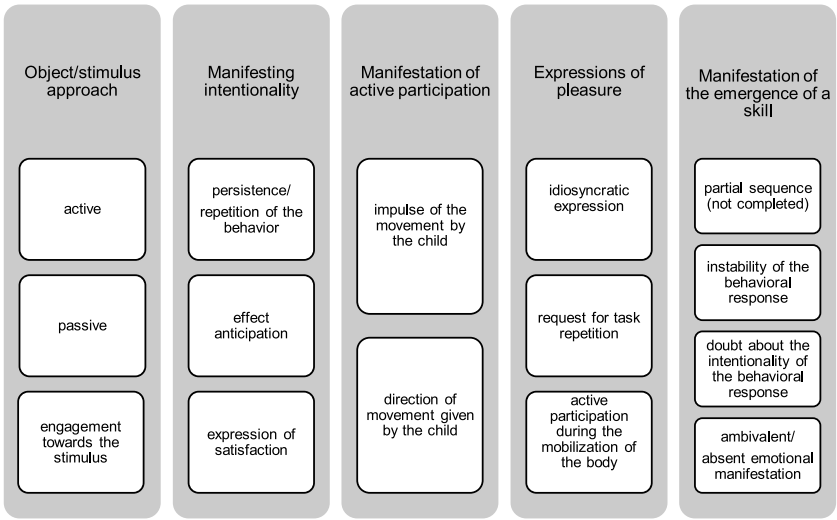

Fig. 3. Categories of behavioral indicators.

Table 3
Operationalization of intentionality indicators.

Intentionality indicators	Operationalization in the battery
Persistence and repetition of behavior	Behavior exhibited at least two times out of three requests
Anticipation of a response/effect	Laughs/smiles/closes eyes/plugs ears/stiffens up before getting the effect
Demonstrating satisfaction when effect is achieved	Laughs/smiles/closes eyes/closes ears/stiffens up right after effect is obtained

Table 4
Demographics of the participants (n = 18).

Variables	Descriptives
Age	Range: 7–12 years ($M = 9.5$, $SD = 1.88$)
Gender	
Female	n = 11 (61 %)
Male	n = 7 (39 %)
Etiology	
Cerebral palsy	n = 5 (28 %)
Hydrocephaly	n = 3 (17 %)
Identified syndromes	n = 10 (56 %)
Gross Motor Functioning*	
Level III	n = 2 (11 %)
Level IV	n = 5 (28 %)
Level V	n = 11 (61 %)
Sensory impairments	
Visual impairments	n = 9 (50 %)
Hearing impairments	n = 1 (6%)
Tactile impairments	n = 9 (50 %)
Health	
Epilepsy	n = 14 (78 %)
Gastrostomy	n = 5 (28 %)
Significant alertness fluctuations	n = 12 (67 %)

Note: *Gross Motor Functioning was defined according to the *Gross Motor Function Classification System* (*GMFCS*) (Palisano et al., 2008).

2.5.2. Participants' variables

The participant's position was adjusted in order to allow as much freedom of movement as possible; postural supports were offered to them to regulate their tonus (e.g., neck supports). The DSWs were instructed to assess before and during each session whether the children were in their normal state of health and alertness, which would not interfere with their ability to pay attention. If this was not the case, the session was deferred or interrupted.

2.5.3. Administration variables

In order to collect data not only on performance at a given session, but also on the magnitude of the intra-individual variability (Maes et al., 2020; Petitpierre et al., 2013), the battery (both lists) was administered three times. The duration of the *SAOL-IT* administration sessions was adapted to each participant in order not to tire them. Between 8 and 13 sessions ($M = 9$ sessions) were required, ranging from 15−27 min ($M = 21$ min). Each session was videotaped. A suitcase of material with attractive objects from a visual, auditory and tactile point of view was created. The object to be used in each of the items was specified, so as to standardize the proposed stimuli from one participant to another. Two items, however, required the use of personal effects belonging to the child. The distance between the stimulus and the child, the speed and the directions of the stimulus, and the stopping times were specified in each item. There was a waiting period of at least 30 s after the instruction was given, according to recommendations about latency time in people with PIMD (Logan et al., 2001; Neerinckx & Maes, 2015).

The validation of the *SAOL-NOS* took place in parallel to the *SAOL-IT*. Eighteen DSWs were instructed to observe and assess the participants with the *SAOL-NOS*, one per participant. Indications were given concerning the natural contexts in which the observation could take place (i.e., during snack time or at morning greeting).

2.6. Score calculation

The first author scored the items of the *SAOL-IT* by watching the video recordings. The DSWs assessed the *SAOL-NOS* items directly after each observation. In both cases, if there was any doubt about the presence of a behavior, the lower score was recorded in order to minimise the risk of over-stating the participant's performance.

In calculating the scores, we took the option of calculating the average scores, i.e., by dividing the total score by the number of items, rather than using the sum of the scores as a basis, as this would have been too sensitive to the number of items per scale. Moreover, calculating the average score means that the scores obtained in the various scales can be compared directly (Taffe, Tonge, Gray, & Einfeld, 2008). The average score was calculated in relation to the items (average of the three measurement occasions), in relation to the scales (average of the scores for the items) and in relation to the whole list (average of the scores for the scales).

2.7. Assessment of the psychometric properties

The psychometric qualities of both lists have been evaluated separately.

2.7.1. Internal consistency

Internal consistency was calculated in both lists using Cronbach's alpha. Internal consistency is considered to be good if the alpha is equal or higher than 0.70 (Nunnally & Bernstein, 1994) or 0.65 (DeVellis, 1991).

2.7.2. Inter-rater reliability

Reliability of the scoring of the items was assessed in the *SAOL-IT* by calculating the inter-rater agreement between the primary investigator and a second independent rater, a scientific collaborator in the field of special needs education, who didn't know the participants. The data of 55 % of the sample ($n = 10$ participants randomly selected, T1, T2 and T3 also randomly selected) were double-coded for each item. The percentage of agreement was estimated by dividing the number of agreements by the sum of agreements and disagreements and multiplying by 100 (Green et al., 1994). It should be pointed out that the threshold for a good level of agreement has been set at 80 % (Cordes, 1994; Kazdin, 1977; Mudford et al., 1997). However, in the field of PIMD some specialists consider that this standard should be more flexible because of the methodological challenges posed by the target group (Maes et al., 2020; Mudford et al., 1997; Vlaskamp & Cuppen-Fonteine, 2007).

Direct observation in the natural context doesn't allow the inter-rater reliability of the *SAOL-NOS* to be measured.

2.7.3. Test-retest reliability

Each item of both lists was administered at three different times of measurement. Intra-class correlation coefficients (ICC; two-way random, absolute agreement) of the three measurements were computed; indeed, calculation of the ICC is recommended when more than two measures are taken (Kim, 2013). Test-retest reliability is considered to be acceptable if the ICC is greater than 0.75 and very good if the ICC is greater than 0.9 (Portney & Watkins, 2000; Waninge, Rook, Dijkhuizen, Gielen, & van der Schans, 2011). In order to confirm the results obtained with the ICC, descriptive analyses (central tendency) and ANOVA analyses have also been conducted.

2.7.4. Intra-rater reliability

Three months after the initial coding of the *SAOL-IT*, the first author re-coded half of the data used in the inter-rater reliability assessment ($n = 5$ participants randomly selected). The percentage of intra-rater reliability was calculated using the same formula as the one used in the assessment of inter-rater reliability.

2.7.5. Procedural reliability

In order to be sure that the performance of the participants is not influenced by the researcher, it is commonly recommended that measures should be taken to ensure that the administration protocol has been implemented in a reliable way (Billingsley, White, & Munson, 1980; Ledford & Gast, 2014). We measured procedural reliability of the administrations of the *SAOL-IT* by making a checklist of six administration variables: the object used, the conditions of presentation of the object/stimulus, the positioning of the researcher, the verbal instruction to the child, the presence of distracting stimuli, the latency time between repetitions of the task. The prescribed and the proscribed administration conditions of each variable were described for each item. A dichotomic score was attributed to quantify both the observance and non-observance of the stipulated conditions (1/0); the order of the prescribed/proscribed conditions was counterbalanced for each item. An independent blind observer to the condition expected (a student in the field of special needs education) coded the administration condition in the videotaped sessions of 35 % of the randomly selected sample ($n = 6$). Procedural reliability was calculated for each administration variable by dividing the number of occurrences of the prescribed condition by the total number of occurrences of the prescribed and proscribed conditions multiplied by 100 (Ledford & Gast, 2014).

2.7.6. Determination of social validity

The social validity of a research study refers to the significance of its aims and the acceptability of its procedure and results (Foster & Mash, 1999). We developed a survey (including both lists) divided into four sections focalizing on : 1) Topic and aim of the research; 2) Method, organization and progress; 3) Benefits for the participants and 4) Benefits for the teachers involved in the experimental phase. The questionnaire was anonymously completed at the end of the data collection by the 18 DSWs involved in the research.

3. Results

We first proceeded to an analysis of the missing data; we found that four items of the *SAOL-IT* could not be administered to the whole sample because they required too complex motor skills, so we removed those items (see Fig. 4). We then conducted a first internal consistency analysis to see if removal of further items was necessary. All the items of the *SAOL-IT* showed a good internal consistency, except for 1 item that we decided to retain for clinical reasons. In contrast, we removed 9 items of the *SAOL-NOS* because of their low internal consistency. The final version of the SAOL-PIMD battery comprises 48 items (30 items in the *SAOL-IT* and 18 items in the *SAOL-NOS)*, as detailed in Table 5.

This final version is characterized by the psychometric properties described in the following paragraphs.

3.1. Reliability

3.1.1. Internal consistency

The overall internal consistency of both lists is excellent (see Table 6). In the *SAOL-IT,* the internal consistency coefficients of the scales are quite satisfactory, except for the "organized self" scale, according to a cut off of 0.65 (DeVellis, 1991). Internal consistency of this scale would be better if the item on divided attention between an auditory and a tactile stimulus were removed. However, we decided to retain it, because its inclusion in this scale is justified on clinical and theoretical reasons. In the *SAOL-NOS*, the internal consistency of two scales (organised and situated self) is good, and lower but still sufficient in three scales (differentiated, agentive and animated self).

3.1.2. Test-retest reliability

Both lists have a high overall test-retest reliability (see Table 6). It may be considered good also for each scale of both lists. The descriptive analysis of the averages at the three times of administration of both lists, as well as an ANOVA test with repeated measurements show that there is no significant difference between the three measurement times $F(2, 34) = .65$, $p = .53$ *(SAOL-IT)*, $F(2, 34) = .49$, $p = .62$ *(SAOL-NOS)*.

3.1.3. Inter-rater reliability

The overall inter-rater agreement was 0.81, which can be considered as good. The agreement for each scale is good to excellent (see

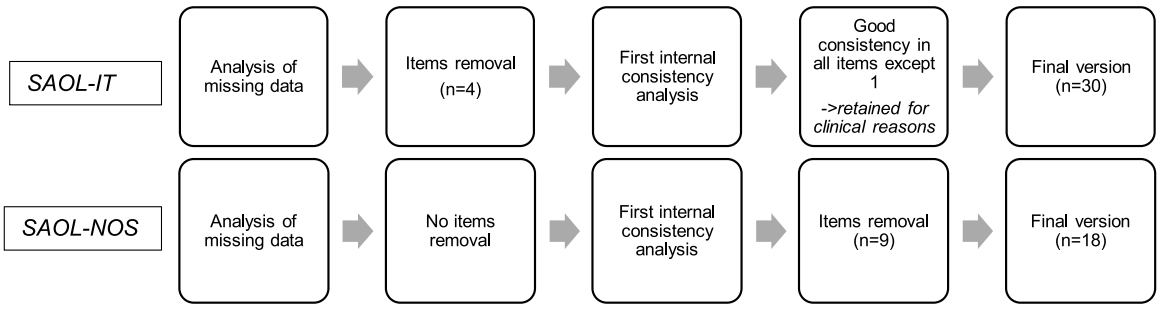

Fig. 4. Items removal process.

Table 5
Final structure of the SAOL-PIMD battery.

Scale	SAOL-IT	SAOL-NOS	Number of items
Differentiated self	4	2	6
Organized self	4	4	8
Agentive self	8	4	12
Situated self	8	5	13
Animated self	6	3	9
Total	30	18	48

Table 6
Consistency and reliability.

Scale	Internal Consistency (Alpha)		Test-retest reliability (ICC)		Inter-rater reliability (weighted percentage)	Intra-rater reliability (weighted percentage)
	SAOL-IT	*SAOL-NOS*	*SAOL-IT*	*SAOL-NOS*	*SAOL-IT*	*SAOL-NOS*
Differentiated self	.707	.550	.856	.947	0.75	0.90
Organized self	.471 (.589*)	.805	.903	.836	0.88	0.88
Agentive self	.787	.461	.955	.979	0.71	0.85
Situated self	.742	.717	.958	.981	0.89	0.93
Animated self	.606	.423	.890	.958	0.78	0.80
Overall	.897	.858	.950	.982	0.81	0.87

Table 6). However, it varies considerably from one participant to another, from 0.66 to 0.97.

3.1.4. Intra-rater reliability

The overall intra-rater reliability was 0.87. The percentage varies from 0.80 to 0.93 depending on the scale.

3.1.5. Procedural reliability

The overall procedural reliability appears to be high. The rate varies from 0.80 to 1.00 depending on the criterion considered (see Table 7*)*.

3.2. Social validity

The questionnaire on social validity was completed by 18 DSWs. Each DSW was present during the administration of the *SAOL-IT,* and each personally administered *SAOL-NOS* to the participant to whom he or she was the usual support worker. The opinions of the DSWs on the four topics investigated were:

a) Need for an observational instrument aimed at self-awareness: self-awareness was perceived as an essential aspect of the development of children with PIMD ($n = 18/18$). The *SAOL-PIMD* was considered to be a valuable tool for professionals ($n = 16/18$).
b) Method, organization and procedure: repetition of measurements ($n = 12/18$), three-point scores ($n = 17/18$), variation of observation contexts ($n = 17/18$), and the content of the tasks ($n = 18/18$) were deemed to be appropriate.
c) Benefits for the participants: according to DSWs, the participants showed interest in the proposed tasks ($n = 17/18$), and the relationship established with the participants by the evaluator during the sessions was deemed to be excellent ($n = 17/18$).
d) Benefits for the DSWs: they considered that they had a better idea of the skills of their pupils at the end of the research ($n = 12/18$) and definite avenues for observation ($n = 16/18$).

4. Discussion

The purpose of this research was to develop and to measure the psychometric qualities of a tool designed for the observation of

Table 7
Procedural reliability.

Variable	Procedural reliability (weighted percentage)
Object used	0.95
Instruction given	0.99
Presentation condition	0.91
Distracting stimulus	0.83
Waiting period	0.80
Positioning	1.00
Overall	0.91

manifestations of ecological self-awareness in children with PIMD. A battery of 61 items, the *SAOL-PIMD*, was created, distributed in two distinct lists according to the context of observations. The *SAOL-IT* was shown to be reliable, with good inter- and intra-rater reliability, high test-retest reliability, high procedural reliability and good internal consistency. The *SAOL-NOS* was shown to have a poorer internal consistency, but a high test-retest reliability. The social validity of the *SAOL-PIMD* is deemed to be excellent.

Self-awareness is a complex concept; constructing a tool for observing the manifestations of self-awareness in people who cannot express themselves with verbal language, and therefore without access to the first-person perspective, is a challenge. The paucity of available specific theoretical frameworks that could lay the foundations for the development of assessment instruments for people with PIMD can be addressed by applying and adapting general theories to this particular group (Maes et al., 2020). We achieved this by basing our instrument on a developmental perspective of self-awareness, both conceptually and methodologically. The good overall internal consistency of both lists can be explained by the robustness of Rochat's multi-dimensional model. It provides a comprehensive understanding of the skills underlying each facet of this form of pre-reflective self-awareness, which facilitated the creation of items classified into five scales. The lower internal consistency of some of the *SAOL-NOS* scales may be explained by the small number of items that make up the final version of this list. The fact that the items were assessed by 18 different DSW may also explain it.

When it comes to inter-rater reliability, several studies have shown that it is difficult to obtain a satisfactory rate of agreement in the observation of the behaviors of individuals with PIMD (Maes et al., 2020; Mudford et al., 1997; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2011; Vlaskamp & Cuppen-Fonteine, 2007). The rate of agreement obtained in our study is particularly high; this can be explained by the precision of the description of the critical, emergent and noncritical behaviors in each item. An accurate description of the responses that may be expressed is invaluable because of the subtlety and complexity of behavioral expressions in children with PIMD, and also for increasing the objectivity of the scoring as far as possible. Concerning the variation in the rate of inter-rater agreement from one participant to another, this phenomenon has been noted in other studies focusing on the same target group (Mudford et al., 1997; Munde et al., 2011). It can be explained by the severity of the person's disabilities or the exceptionally idiosyncratic aspects of some of the behavior displayed by individuals with PIMD. Mudford, Hogg et Roberts (1997) suggest promoting the use of individual definitions of behavior in this regard. Munde et al. (2011) compared the coding of three types of informant: a teacher (the participant's point of contact), an external observer having received information on the child, and an external observer who had received no such information. Their results show a higher level of inter-rater reliability between the observers who know or who have received information on the participants. In the present study, we produced a fact sheet for each participant outlining the main characteristics of their sensory-motor functioning and their expression of emotions, for the benefit of an independent assessor who did not know the participants. This solution appears to offer a sensible compromise.

The test-retest reliability of both lists is very satisfactory, which will somewhat contradict the received view that sometimes considers the performance of individuals with PIMD to be extremely volatile. On the contrary, the results in retests show that if the conditions of administration are properly controlled (attested by the high rate of procedural reliability) and adjusted to allow for the functioning levels of the different participants, the participants may exhibit a certain stability in their behavioral responses. Incorporating repeated measures has proved to be an indispensable precaution for verifying this, as highlighted in Maes et al. (2020).

Of course, in view of certain limitations, a number of comments need to be made about the validation of the *SAOL-PIMD*. The *SAOL-IT* was administered by a single person, which may have had an impact on the psychometric qualities of the list. These should be measured again in future research with the *SAOL-IT* administered by other individuals. Because of its lower internal consistency and the small number of its items, the *SAOL-NOS* should be used as a complementary observation tool to the *SAOL-IT*, without the items being scored. The small size of the sample is also a weakness which didn't allow a factor analysis to be conducted. Small sample sizes are a recurring problem in empirical research with this target group, due to low prevalence rates and their health problems, which can limit their access to research. To overcome this problem, the *SAOL-PIMD* could be administered and validated through international collaborative research (Maes et al., 2020).

5. Conclusion

Summing up, this preliminary validation of a new instrument, the SAOL-PIMD, has yielded some promising results in terms of psychometric properties. Moreover, DSWs have given a positive assessment of its utility. Our research shows that it is possible to create tools for the assessment and direct observation of individuals with PIMD that satisfy the metric qualities required by current scientific standards.

The process of designing the instrument offers a number of methodological options for the creation of this type of tool, adapted to the specific characteristic of individuals with PIMD. First of all, the use of instruments and/or experimental situations employed in developmental psychology research: the tasks proposed for infants can be adapted to the specific characteristics of the target group of individuals with PIMD. The same applies to the methodological paradigms used in these experimental investigations because the dependent variables do not require motor, sensory or perceptive skills that are overly complex. Moreover, the description in each task of the various levels of behavioral responses, and the encoding of these levels, appears to present another promising way forward. They effectively make it possible to make sense of the behavior manifested and to consider it from a developmental perspective – even though these individuals are often subject to a rigid representation of their abilities. Finally, it is essential to test the items with a more balanced representative sample of the entire spectrum of PIMD (Nakken & Vlaskamp, 2007). Cognitive, motor and sensory impairments, which differ considerably from one child with PIMD to the next, make it necessary to pre-test the various options for administration conditions and materials and to look for ways to diversify the sensory modalities of presentation of stimuli.

Beyond its value in providing information on the expressions of self-awareness in children with PIMD, the use of a tool like the SAOL-PIMD could help to fine-tune the observations of professionals and give them ideas for educational activities to promote the

development of greater self-awareness.

Data availability

No data was used for the research described in the article.
Data will be made available on request.

CRediT authorship contribution statement

Juliane Dind: Conceptualization, Methodology, Writing - original draft. **Geneviève Petitpierre:** Supervision.

Acknowledgments

Thanks are extended to the parents of the participants for their consent to their child's participation in this research, as well as to the DSWs for their involvement in the research. The authors would also like to thank the scientific collaborators who assisted them in checking the reliability of the tool.

Appendix A. Content analysis of Rochat's five-facet model

Description of each facet	Corresponding operational behaviors in infants (< 18 months)
Differentiated self	
Ability to discriminate between one's own image and the image of another infant. Ability to differentiate sensations originating from within or outside the body.	Interest in one's specular image. Specular image identification through "post-it test". Differentiated response to own hand contact vs. other's hand contact (single touch versus double touch).
Organized self	
Ability to map the body whereby regions and parts of one's own body are actively and systematically (as opposed to just randomly) put in contact with each other. Ability to make highly organized intermodal experiences).	Hand–mouth coordination. Self-oriented acts. Detection of the difference in textures of objects simultaneously seen and held. Division of attention between a visual and a tactile stimulus
Agentive self	
Ability to act and pay attention to the consequences (visual, auditive, etc.) on the human environment and/or on the physical environment of his/her motor actions. Ability to activate the repertoire of one's sensorimotor responses.	Pressure modulation behaviors on the object being sucked to achieve a sound effect congruent with sucking. Mobilization of the leg to obtain positive reinforcement in a mobile activation experience. Behaviors of anticipation and exploration of the results of one's own actions. Manifestation of anger when a contingent effect to a movement learned by the baby no longer results in the expected effect.
Situated self	
Ability to perceive one's own body as a situated entity in relation to what the environment affords for action and as an invariant spatial structure. Ability to locate sensory events in their environment. Ability to take into account the spatial properties of objects.	Place hands on the objects they see in their grip space, differentiated reaction if the objects are located in or outside the grip space. Imitation behaviors. Orientation and stimulus tracking behaviors. Adaptation of reaching gestures according to the spatial properties of objects. Identification of the reverse side of objects. Understanding of the container-content relationship. Detour behavior (e.g., to reach an object partially hidden behind an obstacle).
Animated self	
Ability to explore one's body and engage in a perceptual dialogue with oneself. Ability to calibrate the effectiveness of one's movements, as well as to specify one's own strength and vitality.	Babbling, exploring their own voice. Contemplation by babies of their hand and leg movements.

References

Billingsley, F., White, O. R., & Munson, R. (1980). Procedural reliability: A rationale and an example. *Behavioral Assesment, 2*, 229–241.
Blanke, O., & Metzinger, T. (2009). Full-body illusions and minimal phenomenal selfhood. *Trends in Cognitive Sciences, 13*(1), 7–13. https://doi.org/10.1016/j.tics.2008.10.003
Blanke, Olaf, Slater, Mel, & Serino, Andrea (2015). Behavioral, Neural, and Computational Principles of Bodily Self-Consciousness. *Neuron, 88*(1), 145–166. https://doi.org/10.1016/j.neuron.2015.09.029

Brisson, A., Bujold, E., & Lemay, J. (2011). *Programme éducatif destiné aux élèves ayant une déficience intellectuelle profonde. Programme de formation de l'école québécoise [Education Program for Students with a Profound Intellectual Deficiency]. Québec Education Program*. Gouvernement du Québec. http://www.education.gouv.qc.ca/fileadmin/site_web/documents/dpse/formation_jeunes/ProgEducDestineElevesDefIntelProfonde_PFEQ_f.pdf.

Butterworth, G. (2000). An ecological perspective on the self and its development. In D. Zahavi (Ed.), *Exploring the self. Philosophical and psychopathological perspectives on self-experience* (pp. 19–38). John Benjamins Publishing Company.

Cordes, A. K. (1994). The reliability of observational data. *Journal of Speech Language and Hearing Research, 37*(2), 264–279. https://doi.org/10.1044/jshr.3702.264

Council for the Curriculum, E. and A. (2007). *Quest for learning*. Council for the Curriculum Examinations and Assessment. http://www.nicurriculum.org.uk/docs/inclusion_and_sen/pmld/quest_guidance_booklet.pdf.

Curriculum and Qualifications Group. (2006). *Routes for Learning. Assessment materials for learners with profound learning difficulties and additional disabilities*. Welsh Assembly Government.

Damasio, A. R. (1999). *Le sentiment même de soi. Corps, émotions, conscience [The feeling of what happens: Body and Emotion in the making of Consciousness]*. Odile Jacob.

DeVellis, R. F. (1991). *Scale development: Theory and applications*. Sage Publication.

Dind, J. (2018). *Les manifestations de la conscience de soi chez l'enfant polyhandicapé. Edification d'un outil d'observation au service des professionnels [Manifestations of self-consciousness in children with PIMD: Building an observational tool for professionals]*. Université de Fribourg. http://doc.rero.ch/record/306941.

Dind, J. (2020). *La conscience de soi au prisme du polyhandicap. Mieux la connaître, l'observer et stimuler son développement [Self-consciousness seen through the prism of PIMD: Getting to know it better, observe it and stimulate its development]*. Edizioni Fondazione ARES.

Dolan, R. J. (1999). Feeling the neurobiological self. The self may be defined in terms of responses to experience. *Nature, 401*, 847–848.

Duff, C. K., & Flattery, J. J. (2014). Developing mirror self awareness in students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(5), 1027–1038. https://doi.org/10.1007/s10803-013-1954-0

Ehrsson, H. H. (2007). The experimental induction of out-of-body experiences. *Science, 317*(5841), 1048. https://doi.org/10.1126/science.1142175

Faivre, N., Arzi, A., Lunghi, C., & Salomon, R. (2017). Consciousness is more than meets the eye: A call for a multisensory study of subjective experience. *Neuroscience of Consciousness, 2017*(1), 1–8. https://doi.org/10.1093/nc/nix003

Foster, S. L., & Mash, E. J. (1999). Assessing social validity in clinical treatment research: Issues and procedures. *Journal of Consulting and Clinical Psychology, 67*(3), 308–319. https://doi.org/10.1037/0022-006X.67.3.308

Green, C. W., Gardner, S. M., Canipe, V. S., & Reid, D. H. (1994). Analyzing alertness among people with profound multiple disabilities: Implications for provision of training. *Journal of Applied Behavior Analysis, 27*(3), 519–531. https://doi.org/10.1901/jaba.1994.27-519

Hobson, P. R., Chidambi, G., Lee, A., & Meyer, J. (2006). *Foundations for self-awareness: An exploration through autism*. Blackwell Publishing Inc.

Josse, D. (1997). Brunet-Lézine révisé. *Echelle de développement psychomoteur de la première enfance [Brunet-Lézine revised. The Scale of Psychomotor Development of Children]*. Etablissements d'Applications Psychotechniques.

Kazdin, A. E. (1977). Artifact, bias, and complexity of assessment: The ABCs of reliability. *Journal of Applied Behavior Analysis, 10*(1), 141–150. https://doi.org/10.1901/jaba.1977.10-141

Kim, H.-Y. (2013). Statistical notes for clinical researchers: Evaluation of measurement error 1: Using intraclass correlation coefficients. *Restorative Dentistry & Endodontics, 38*(2), 98–102.

Kircher, T., & David, A. (2003a). Self-consciousness: An integrative approach from philosophy, psychopathology and the neurosciences. In T. Kircher, & A. David (Eds.), *The self in neuroscience and psychiatry* (pp. 445–474). Cambridge University Press.

Kircher, T., & David, A. (2003b). *The self in neuroscience and psychiatry*. Cambridge University Press.

Laveault, D., & Grégoire, J. (2014). *Introduction aux théories des tests en psychologie et en sciences de l'éducation [Introduction to the theories of tests in psychology and sciences of education] (3ème)*. De Boeck.

Ledford, J. R., & Gast, D. L. (2014). Measuring procedural fidelity in behavioural research. *Neuropsychological Rehabilitation, 24*(3–4), 332–348. https://doi.org/10.1080/09602011.2013.861352

Lenggenhager, B., Tadi, T., Metzinger, T., & Blanke, O. (2007). Video ergo sum: Manipulating bodily self-consciousness. *Science, 317*(5841), 1096–1099. https://doi.org/10.1126/science.1143439

Logan, K. R., Jacobs, H. A., Gast, D. L., Smith, P. D., Daniel, J., & Rawls, J. (2001). Preferences and reinforcers for students with profound multiple disabilities: can we identify them? *Journal of Developmental and Physical Disabilities, 13*(2), 97–122.

Lyons, V., & Fitzgerald, M. (2013). Atypical sense of self in autism spectrum disorders: A neuro-cognitive perspective. In M. Fitzgerald (Ed.), *Recent advances in autism spectrum disorders* (Volume 1, pp. 749–770). InTech.

Maes, B., Nijs, S., Vandesande, S., Van keer, I., Arthur-Kelly, M., Dind, J., et al. (2020). Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(1), 250–262. https://doi.org/10.1111/jar.12803

Mechling, L. C., & Bishop, V. A. (2011). Assessment of computer-based preferences of students with profound multiple disabilities. *The Journal of Special Education, 45*(1), 15–27. https://doi.org/10.1177/0022466909348661

Morin, A. (2006). Levels of consciousness and self-awareness: A comparison and integration of various neurocognitive views. *Consciousness and Cognition, 15*(2), 358–371. https://doi.org/10.1016/j.concog.2005.09.006

Mudford, O. C., Hogg, J., & Roberts, J. (1997). Interobserver agreement and disagreement in continuous recording exemplified by measurement of behavior state. *American Journal on Mental Retardation, 102*(1), 54–66. https://doi.org/10.1352/0895-8017%281997%29102%3C0054%3AIAADIC%3E2.0.CO%3B2

Munde, V., Vlaskamp, C., Ruijssenaars, W., & Nakken, H. (2011). Determining alertness in individuals with profound intellectual and multiple disabilities: The reliability of an observation list. *Education and Training in Autism and Developmental Disabilities, 46*(1), 116–123.

Nader-Grosbois, N. (2013). Les échelles d'évaluation du développement cognitif précoce. Utilité pour des personnes avec un polyhandicap [scales for assessment of early cognitive development. Usefulness for people with PIMD]. In R. Scelles, & G. Petitpierre (Eds.), *Polyhandicap: Processus d'Evaluation Cognitive* (pp. 157–178). Dunod.

Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(2), 83–87. https://doi.org/10.1111/j.1741-1130.2007.00104.x

Neerinckx, H., & Maes, B. (2015). Joint attention behaviours in people with profound intellectual and multiple disabilities: The influence of the context. *Journal of Applied Research in Intellectual Disabilities, 29*, 574–584. https://doi.org/10.1111/jar.12217

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (third edit). McGraw-Hill Series in Psychology. http://psycnet.apa.org/psycinfo/2003-00036-000.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised gross motor function classification system. *Developmental Medicine and Child Neurology, 50*, 744–750.

Petitpierre, G., & Gyger, J. (2014). *Mallette socio-pédagogique pour l'accompagnement des personnes adultes avec un polyhandicap ou une dificience intellectuelle sévère [Socio-educational package to support adults with PIMD]*. Fondation Eben-Hézer, Université de Fribourg & Genève.

Petitpierre, G. (2013). Cognition, émotions, sensations mouvements [Cognition, emotions, sensations, movements]. In G. Petitpierre, & R. Scelles (Eds.), *Polyhandicap: processus d'évaluation cognitive* (pp. 53–74). Dunod.

Portney, L. G., & Watkins, M. P. (2000). *Foundations of clinical research* (2nd.ed). Prentice-Hall.

Rochat, P. (1993). Connaissance de soi chez le bébé [Self-knowledge in infancy]. *Psychologie Française, 38*(1), 41–51.

Rochat, P. (2006). *Le monde des bébés [The Infant's World]*. Odile Jacob.

Rochat, P. (2009). *Others in mind. Social origins of self-consciousness*. Cambridge University Press.

Rochat, P. (2010). Sens de soi et sens de l'Autre au début de la vie [Sense of self and sense of others early in life]. In A. Berthoz, & B. Andrieu (Eds.), *Le Corps en Acte* (pp. 59–67). Presses Universitaires de Nancy.

Rochat, P. (2011). The self as phenotype. *Consciousness and Cognition, 20*(1), 109–119. https://doi.org/10.1016/j.concog.2010.09.012

Rochat, P. (2012). Primordial sense of an embodied self-unity. In V. Slaughter, & C. A. Brownell (Eds.), *Early development of body representations* (pp. 3–18). Cambridge University Press.
Rochat, P. (2014). Développement de la conscience de soi [Development of self-consciousness]. *Bulletin Scientifique de l'arapi* (p. 32).
Rochat, P. (2016). Roots of typical consciousness: Implications for developmental psychopathology. In D. Cicchetti (Ed.), *Developmental psychopathology* (pp. 1–31). John Wiley & Sons, Inc.. https://doi.org/10.1002/9781119125556.devpsy110
Rochat, P. (2003a). Five levels of self-awareness as they unfold early in life. *Consciousness and Cognition, 12*(4), 717–731. https://doi.org/10.1016/S1053-8100(03)00081-3
Rochat, P. (2015a). Engagement global du corps et connaissance précoce [Global engagement of the body and early cognition]. *Enfance, 2015*(4), 453–462. https://doi.org/10.4074/S0013754515004061
Rochat, P. (2003b). Conscience de soi et des autres au début de la vie [Self-knowledge and social knowledge early in life]. *Enfance, 55*(1), 39–47. https://doi.org/10.3917/enf.551.0039
Rochat, P. (2015b). The innate experience of self-agency. In P. Haggard (Ed.), *The sense of agency* (pp. 251–264). Oxford University Press Social Cognition and Social Neuroscience series.
Rochat, P., & Goubet, N. (2000). Connaissance implicite du corps au début de la vie [Implicit knowledge of the body early in life]. *Enfance, 53*(3), 275–285. https://doi.org/10.3406/enfan.2000.3184
Rodi, A. (2013). *Projet "PER-EDISP". Projet d'adaptation du Plan d'Etude Romand pour les élèves ayant une déficience intellectuelle sévère/profonde ou un polyhandicap "PER-EDISP" Project. Project to adapt the Plan d'Etude Romand for pupils with PIMD*.
Rust, J., & Golombok, S. (2009). *Modern psychometrics* (3rd). Routledge. https://doi.org/10.4324/9781315787527
Salomon, R., Noel, J. P., Łukowska, M., Faivre, N., Metzinger, T., Serino, A., et al. (2017). Unconscious integration of multisensory bodily inputs in the peripersonal space shapes bodily self-consciousness. *Cognition, 166*, 174–183. https://doi.org/10.1016/j.cognition.2017.05.028
SIRG-PIMD. (2001). Newsletter special interest research group 'Individuals with profound multiple disabilities. *Newsletter SIRG-PIMD*. https://www.iassidd.org/profound-intellectual-and-multiple-disabilities/.
South Lanarkshire Council. (2015). *The South Lanarkshire framework for supporting pupils with severe and profound learning needs. Curriculum for excellence*. Education Resources.
Squillaci Lanners, M. (2005). *Polyhandicap. Le défi pédagogique [PIMD: The educational challenge]* (edition szh/csps).
Tadema, A., Vlaskamp, C., & Ruijssenaars, W. (2005). The development of a checklist of child characteristics for assessment purposes. *European Journal of Special Needs Education, 20*(4), 403–417. https://doi.org/10.1080/08856250500268643
Taffe, J. R., Tonge, B. J., Gray, K. M., & Einfeld, S. L. (2008). Extracting more information from behaviour checklists by using components of mean based scores. *International Journal of Methods in Psychiatric Research, 17*(4), 232–240. https://doi.org/10.1002/mpr.260
Uzgiris, I. C., & Hunt, J. M. (1980). *Assesment in infancy. Ordinal scales of psychological development* (4th ed.). University of Illinois Press.
van Timmeren, E. A., van der Putten, A. A. J., van Schrojenstein Lantman-de Valk, H. M. J., van der Schans, C. P., & Waninge, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: A cross-sectional study of medical records and care plans. *Journal of Intellectual Disability Research, 60*(11), 1109–1118. https://doi.org/10.1111/jir.12298
Vlaskamp, C. (2005). Assessing people with profound intellectual and multiple disabilities. In J. Hogg, & A. Langa (Eds.), *Assessing adults with intellectual disabilities* (pp. 152–163). BPS Blackwell.
Vlaskamp, C., & Cuppen-Fonteine, H. (2007). Reliability of assessing the sensory perception of children with profound intellectual and multiple disabilities: A case study. *Child: Care, Health and Development, 33*(5), 547–551. https://doi.org/10.1111/j.1365-2214.2007.00776.x
Vlaskamp, C., Van der Meulen, B., & Smrkovsky, M. (2002). *Behavioural Appraisal Scales BAS for people with profound intellectual and multiple disabilitiesStichting Kinderstudies*. Open access document.
Waninge, A., Rook, R. A., Dijkhuizen, A., Gielen, E., & van der Schans, C. P. (2011). Feasibility, test-retest reliability, and interrater reliability of the Modified Ashworth Scale and Modified Tardieu Scale in persons with profound intellectual and multiple disabilities. *Research in Developmental Disabilities, 32*(2), 613–620. https://doi.org/10.1016/j.ridd.2010.12.013
Wessels, M. D., Paap, M. C. S., & Van der Putten, A. A. J. (2020). Validity of an instrument that assesses functional abilities in people with profound intellectual and multiple disabilities: Look what I can do! *Journal of Intellectual & Developmental Disability*, 1–11. https://doi.org/10.3109/13668250.2020.1785851
Zelazo, P. D. (1996). Towards a characterization of minimal consciousness. *New Ideas in Psychology, 14*(1), 63–80. https://doi.org/10.1016/0732-118X(96)00004-9