Received: 6 March 2019 | Revised: 1 November 2019 | Accepted: 7 December 2019

DOI: 10.1111/jar.12697

ORIGINAL ARTICLE

JARID Journal of Applied Research in Intellectual Disabilities bild WILEY

Standardizing the assessment of emotional development in adults with intellectual and developmental disability

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Abstract

Objective: The Scale of Emotional Development—Short (SED-S) is an instrument to assess the level of emotional development (ED) in people with intellectual and developmental disability. Index cases are developed as a didactic tool to standardize the application of the scale.

Method: In a stepwise process, a European working group from six countries developed five index cases, one for each level of ED. All cases were first scored by 20 raters using the SED-S and then rephrased to reduce inter-rater variations ($SD > 0.5$).

Results: All five index cases yielded overall ratings that matched the intended level of ED. Across the range of ED, *Regulating Affect* needed rephrasing most to ensure a distinct description within each level of ED.

Conclusions: The tri-lingual, cross-cultural evolution of five index cases contributes to a standardized application of the SED-S and can serve as training material to improve the inter-rater reliability of the SED-S across different cultures and languages.

KEYWORDS

adults, emotional development, intellectual disability, mental health, scale, standardized assessment

1 | INTRODUCTION

Individuals with intellectual and developmental disability (IDD) show a high prevalence of mental health problems (around 40%), including affective and psychotic disorders as well as dementia, autism spectrum disorders, pica and sleep disorders. The most prevalent clinical presentation, however, is problem behaviour (around 20%) (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). The latter may be derived from many different factors, which have to be carefully identified for every single behaviour in every single individual, such as physical pain, drug side effects, psychological distress, environmental issues, reward search or a combination of these. Some studies identified a relationship between problem behaviours and

psychiatric disorders (Emerson, Moss, & Kiernan, 1999; Felce, Kerr, & Hastings, 2009; Hemmings, Gravestock, Pickard, & Bouras, 2006; Kishore, Nizamie, & Nizamie, 2005; Moss et al., 2000; Rojahn, Matson, Naglieri, & Mayville, 2004), especially in individuals with severe IDD. Other studies did not find any evidence for the possibility that problem behaviours can be considered as behavioural equivalents of psychiatric symptoms but instead considered them to be an expression of general emotional dysregulation (Melville et al., 2016; Rojahn & Meier, 2009; Tsiouris, Mann, Patti, & Sturmey, 2003). When considering emotional functioning, the assessment of emotional development (ED) may bring an additional perspective to the mechanisms leading to problem behaviours. Indeed, the impact of the emotional developmental aspects is gaining increasing attention from practitioners working in the field of IDD (de Bruijn, Vonk, Van den Broek, & Twint, 2017; Došen, Hennicke, & Seidel, 2018; Morisse & Došen, 2017; Sappok et al., 2014; Sappok & Zepperitz, 2016; Sappok, Zepperitz, Barrett, & Došen, 2018).

In this study, ED was conceptualized according to the dynamic model of ED of Došen (2007) and Došen (2018). The concept of ED comprises different aspects of emotional functioning, such as object permanency, relating to significant others, differentiation and regulation of emotions, impulse control and mentalizing abilities (de Bruijn et al., 2017; Došen, 2018; Sappok & Zepperitz, 2016). Various competencies are acquired in a social context along the normative developmental trajectory, and these lead to a further maturation of the individual. As such, ED occurs in coordination with various processes, including cognitive, sexual, motor and moral development (Sroufe, 1995). Being aware that development is a continuous process, a person's level of ED is defined in a stepwise model according to the central characteristic of a certain age group. Each stage is associated with specific emotional needs, motivations and coping skills, which affects a person's ability to adapt to the environment (Sappok et al., 2016, Sappok, 2018).

The developmental approach shows potential as a "diagnostic aid" for services supporting people with IDD and leads to a better understanding of the origins and severity of problem behaviours (Sappok et al., 2014). For example, a person's level of ED can be used to help identify autism spectrum disorder in people with IDD (Sappok et al., 2013) and "aggression regulation," a domain within the original Scale of Emotional Development, can be useful in the identification of vulnerability factors to some problem behaviours (Böhm, Dziobek, & Sappok, 2018).

Furthermore, accounting for the basic emotional needs arising from a certain level of ED may increase well-being, stimulate further personality development, and result in the acquisition of functional life skills in people with IDD (Došen, 2007; Frankish, 2013; Sappok, Schade, Kaiser, Došen, & Diefenbacher, 2012). Subsequently, better-tailored treatment options may arise, including the reduction or withdrawal of eventual pharmacological treatment (Barrett, 2017). For service-providers, considering the level of ED may also help to improve the interpersonal relationship and bonding between the person with IDD and their caregivers (Sappok & Zepperitz, 2016).

Assessing ED is often considered an important addition in the characterisation of the person with IDD, beyond their level of cognitive functioning, as determined by measures of intelligence. Indeed, despite the high correlation between IDD and ED, discrepancies between cognitive and emotional development have been found repeatedly (Böhm et al., 2018). Therefore, it is not appropriate to equate the severity of IDD with the level of ED; instead, the level of ED should be assessed separately.

The Network of Europeans on Emotional Development (NEED) was founded in May 2015 in Berlin, Germany, during a first international study week of clinicians, practitioners and researchers from Germany, Belgium and the Netherlands. Later, the group was complemented by new members from the United Kingdom, Italy and Switzerland. The aim of this network is to facilitate theory development and research on ED, and to ensure high quality in the clinical implementation of the approach. In the first step, NEED developed a standardized instrument to assess the level of ED, namely the *Scale of Emotional Development—Short* (Sappok et al., 2016). The SED-S measures the level of ED in a stepwise model, comprising five different stages in eight different aspects of development, the so-called domains (details c.f. methods; Sappok et al., 2016). The process of developing the SED-S, and the associated case discussions, began to align cross-cultural differences in the judgement of the level of ED in people with IDD.

The clinical value of an instrument depends on its objectivity, validity and reliability. Training of the assessors is pivotal to optimize inter-rater reliability. Thus, the aim of the current study was to develop standardized index cases, one for each level of ED, to support the calibration of the assessors. The index cases may further be used for the purpose of training assessors in different countries and settings to improve the standardization of the application of the scale on an international level.

2 | METHOD

2.1 | Study design

1. In the first step, the NEED group prepared five video-supported index cases (tasks were divided within the group). Each participant of the NEED meeting (N = 23) rated each SED-S case on his or her own. Finally, the various scores were made public, and controversial ratings were discussed in the group. This process uncovered hitherto unknown differences in the judgement of the different applicants, including cultural aspects.
2. In the next step, the behaviour as shown on the video was described in the index cases. These case descriptions were a composite of different persons for didactic reasons and to ensure anonymity. In these cases, vignettes, that is, phrases that are identical to the items in the scale, were avoided. Therefore, the reader needs to interpret a described behaviour (e.g. in Case 2: "Autumn is his favourite time of the year, and he loves hearing the leaves rustle, playing with them and ripping them apart.") and

reference it to scale items (in this example, two items in domain 6, phase 2: "*Explores/examines materials and objects by kneading, hitting and shaking them*" and "*Reaches for things he/she can see or hear*"). Again, tasks were divided within the group. These written descriptions of persons with characteristic behaviours for each level of ED were translated into German, Dutch and English. Several review processes aligned wording differences between the three languages in each case.

3. In the third step, these written case descriptions were separately rated by 20 participants from six different countries and nine different study sites: three participants from the Netherlands, eleven participants from three facilities in Germany, three participants from Belgium, one from the United Kingdom, one from Switzerland and one from Italy. The professional backgrounds were seven psychologists, seven ortho-pedagogues, four medical doctors, one music therapist and one nurse. Nine of these raters were not present when the videotaped index cases were originally rated, and therefore, they were unfamiliar with all cases. All raters were blinded to the domain and overall level of ED of the five presented cases. However, the five participants responsible for the written case descriptions were un-blinded to their respective case. All raters were experienced in the ED approach and the application of the SED-S.

Medians were chosen as the final results for the assessment of each domain, as these assign a distinct level of ED and tolerate outliers. Standard deviations below 0.5 were accepted as appropriate because variations between the raters below 0.5 did not lead to a different judgement. Domains with $SD > 0.5$ were rephrased in all index cases by participants who did not contribute to the development of the index cases and therefore were able to more objectively describe the behaviour within that domain. The index cases were then checked by the participant originally responsible for the respective case description.

4. Rephrasing took place in English in the first instance and was applied to the German and Dutch versions in the final step. The translations were controlled in a comprehensive review process by the authors of this paper.

2.2 | The SED-S instrument

In 2015, researchers from Belgium, the Netherlands and Germany (NEED) met for a "scientific week" in Berlin to develop a valid and reliable instrument for the assessment of ED (details c.f. Sappok et al., 2016). In a cross-cultural effort, this group devised a short, psychometrically sound instrument for evaluation of the level of ED in individuals with IDD: the *Scale of Emotional Development—Short* (SED-S; Sappok et al., 2016). The SED-S items are based on the *Scale for Emotional Development—Revised*[2] (SED-R[2]; Morisse & Došen, 2017). The SED-S consists of 200 binary items (five per level of ED), describing five levels of emotional functioning within eight domains: (1) Relating to His/Her Own Body, (2) Relating to Significant Others, (3) Dealing with Change—Object Permanence, (4) Differentiating Emotions, (5) Relating to Peers, (6) Engaging with the Material World, (7) Communicating with Others and 8) Regulating Affect. The five levels of emotional functioning were derived from the staged model proposed by Došen (2018): Adaptation (0–6 months), Socialization (7–18 months), First Individuation (19–36 months), Identification (4–7 years) and Reality Awareness (8–12 years).

The scale is administered as a semi-structured interview by a trained clinician (e.g. psychologist, ortho-pedagogue or psychiatrist) with informants from several different areas of the client's life (e.g. living, working, therapy and family life). For each domain, the stage with the highest number of items rated as "typical" is assumed to provide the best estimation of the client's level of ED in that particular domain. For an overall result, a rank-based strategy was chosen, with the highest level of ED within the four lowest ranking domains determining the overall level of ED. Sappok et al. (2016), Morisse, Sappok, De Neve, and Došen (2017), and Sappok et al. (2018) reported the administration and scoring of the SED-S in detail.

2.3 | Ethics

Informed consent for voluntary participation was sought and obtained for the video recordings of every participant from each participant or from his or her legal guardian, and confidentiality and anonymity were respected. In accordance with this right, many identifying details of index cases, which were not relevant for the assessment procedure, were changed to protect the privacy of individuals. Moreover, the case descriptions were combined from different persons for didactic reasons and to reduce recognition of the described persons.

Activities for the present research were carried out by the authors and other contributors within their regular working time and in voluntary time, as there was no additional funding for the paper.

2.4 | Data analysis

For each index case, the median, mean, standard deviation, minimum value and maximum value were calculated for the 20 ratings in each domain. There were only a few missing values ($n = 4/800$). These values were not included in the analysis. The median values were chosen as decisive results in the respective domain and case. For those domains with a $SD > 0.5$, the descriptions of the index cases were later rephrased to allow a distinct rating of each aspect in each case example. To measure inter-rater reliability, the intraclass correlation (ICC; two-way random model, single measures, absolute agreement) was assessed. The means (on domain and overall level) of the raters present at the first meeting ($n = 11$) and of those totally unfamiliar with the cases shown in the first meeting ($n = 9$) were compared using Mann–Whitney U tests. The inter-rater agreement was measured as agreement with the mean rating and compared between the two groups of raters. Hereby, missing values were conservatively counted as disagreement.

3 | RESULTS

3.1 | Results from the ratings of the five index cases

All five index cases yielded overall ratings that matched the intended level of ED. The median values mark the consensus rating of each case in each domain. The median value for each domain fell between two different levels of ED in only one case (Case 1, domain 3). As the standard deviation was also high, the description of behaviour relevant for domain 3 was rephrased to result in a clear level 2 of ED.

Table 1 summarizes the minimum and maximum, the mean, the standard deviation, and the median value for each case, encompassing the eight domains and the overall result.

Aspects with a significant inter-rater-variation (standard deviation>0.5. marked in bold in Table 1) needed rephrasing to ensure a distinct description for each domain within each level of ED. As mentioned above, in index case 1, one domain showed a standard deviation above 0.5. In this instance, the results were not decisive for the 20 raters; therefore, these aspects needed to be clarified by an additional review process. Similarly, four domains in index case 2, three domains in index case 3, two domains in index case 4 and five domains in index case 5 needed to be rephrased due to the significantly increased standard deviations. The findings for domain 8 "*Regulating Affect*," were the most frequently unclear, whilst domain 5 "*Relating to Peers*" and domain 7 "*Communicating with Others*" needed to be rephrased only once.

The ICC was assessed on domain and overall level and is also displayed in Table 1. The domain values ranged from 0.846 for domain 8 "*Regulating Affect*" to 0.938 for domain 1 "*Relating to His/Her own Body.*" The ICC for the overall scale value was 0.942.

Figure 1 shows the results from the SED-S scores of the independently coded index cases on domain and overall level of ED. The overall results clearly indicate the assigned level of ED. Index cases 1 and 3 show a higher or lower score on domain 3 "*Dealing with Change—Object Permanence.*" Furthermore, index case 3 shows a lower score on domain 2 "*Relating to Significant Others.*" The same applies to index case 2 on domain 4 "*Differentiating Emotions*" and index case 5 on domain 8 "*Regulating Affect*."

3.2 | Comparison between raters familiar and unfamiliar with the original case presentation

We also compared the ratings of those eleven raters who had been involved in the development of the cases in Ghent and those nine raters who were unfamiliar with the cases. The means of the familiar and unfamiliar raters differed between −0.46 and 0.51, the standard deviations between −0.54 and 0.31, and the medians in 3 out of the 40 domains of a maximum of 1 ED level. The medians on the overall scale level did not differ between the two groups.

Looking at the differences in all 5 × 8 domains and the 5 overall ratings, no differences in the means between the familiar and the unfamiliar raters were found (45 nonsignificant Mann–Whitney *U* tests all yielding $p > .05$).

The level of inter-rater agreement was 81.8% across all cases and dimensions. It did not differ significantly between experienced raters (80.8%) and unexperienced raters (83.0%) ($\chi^2 = 0.694$ < chi-square 3.84 ($df = 1$; $p = 0.95$).

3.3 | Final descriptions of the five index cases

Table 2 reports the final English versions of the five index cases.

The respective translations in Dutch and German are shown in the supplement.

4 | DISCUSSION

The main outcome of this study is the development of five index cases, one for each level of ED, as a didactic tool to standardize the application of the SED-S. This may contribute to more standardized research, as the index cases can be used in the training of raters and in clinical practice to provide a more standardized assessment of the level of ED in people with IDD.

Although there was an overall agreement for the level of ED on the scale level, there was variation in some domains regarding the ease or difficulty of the scoring, and the index cases needed to be adapted to improve the standardized scoring. This difficulty in scoring may also indicate that the SED-S items on domain 8 "*Regulating Affect*" need revision. In addition, analysis on the item level may contribute to a more standardized scoring of the SED-S on domain 1 "*Relating to His/Her Own Body*," domain 2 "*Relating to Significant Others*," domain 3 "*Dealing with Change—Object Permanence*," domain 4 "*Differentiating Emotions*" and domain 6 "*Engaging with the Material World*."

Assessment of the level of ED is supportive for treatment and care for persons with IDD and additional mental health problems or problem behaviours (Došen, 2018; Sappok & Zepperitz, 2016). When people with IDD emotionally function below their level of cognitive development, there is a major risk for the development of problem behaviours (Böhm et al., 2018; Sappok et al., 2014). This may be caused by unrecognized emotional needs and demands regarding their ability to understand and solve situations on their own that cannot be resolved by the individual (Došen, 2018; Sappok & Zepperitz, 2016). Interestingly, the SED domain "aggression regulation" is particularly associated with more severe problem behaviours (Böhm et al., 2018). Indeed, emotional functioning might mediate the correlation between the severity of IDD and adaptive functioning, as suggested by Otsuka, Uono, Yoshimura, Zhao, and Toichi (2017). This is supported by the high correlation between the level of ED and adaptive behaviours, as measured with the Vineland Scale (La Malfa, Lassi, Bertelli, Albertini, & Došen, 2009). Thus, it is not the severity of IDD but rather the frequently associated impairments of emotional functioning that may be the crucial

TABLE 1 Results of the 20 independently coded SED-S assessments for each index case

	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Overall result
Case 1									
Min/Max	1/2	1/1	1/3	1/1	1/1	1/2	1/2	1/1	1/1
Mean (*SD*)	1.1 (0.3)	1 (0)	1.55 **(0.59)**	1 (0)	1 (0)	1.25 (0.43)	1.1 (0.3)	1 (0)	1 (0)
Median	1	1	1.5	1	1	1	1	1	1
Case 2									
Min/Max	1/3	2/3	1/3	1/2	1/3	1/3	2/3	1/3	2/3
Mean (*SD*)	2.05 **(0.5)**	2.05 (0.22)	2.10 (0.44)	1.95 (0.22)	1.75 **(0.94)**	2.15 **(0.48)**	2.06 (0.23)	2.20 **(0.6)**	2.05 (0.22)
Median	2	2	2	2	1	2	2	2	2
Case 3									
Min/Max	3/3	2/3	2/4	2/3	3/3	2/3	2/3	2/3	2/3
Mean (*SD*)	3.00 (0)	2.30 **(0.46)**	2.30 **(0.64)**	2.70 **(0.46)**	3.00 (0)	2.85 (0.36)	2.95 (0.22)	2.90 (0.3)	2.90 (0.3)
Median	3	2	2	3	3	3	3	3	3
Case 4									
Min/Max	4/5	4/5	4/5	3/5	4/5	4/5	3/5	3/5	4/5
Mean (*SD*)	4.10 (0.3)	4.10 (0.3)	4.16 (0.36)	4.00 (0.32)	4.15 (0.36)	4.35 **(0.48)**	4.05 (0.39)	4.05 **(0.5)**	4.05 (0.22)
Median	4	4	4	4	4	4	4	4	4
Case 5									
Min/Max	4/5	3/5	4/5	3/5	4/5	5/5	3/5	3/5	3/5
Mean (*SD*)	4.65 **(0.48)**	4.55 **(0.67)**	4.95 (0.22)	4.30 **(0.9)**	4.90 (0.3)	5.00 (0)	4.50 **(0.74)**	4.05 **(0.86)**	4.60 **(0.66)**
Median	5	5	5	5	5	5	5	4	5
ICC	0.938	0.929	0.897	0.886	0.918	0.894	0.923	0.846	0.942
Number of cases with *SD* > 0.5	2	2	2	2	1	2	1	3	1

Note: (1) Relating to His/Her Own Body, (2) Relating to Significant Others, (3) Dealing with Change – Object Permanence, (4) Differentiating Emotions, (5) Relating to Peers, (6) Engaging with the Material World, (7) Communicating with Others, and (8) Regulating Affect.

Min: minimum value; Max: maximum value; *SD*: standard deviation; *SD* > 0.5 is marked in bold; ICC: intraclass correlation, two-way random model, single measures, absolute agreement; confidence interval 95%.

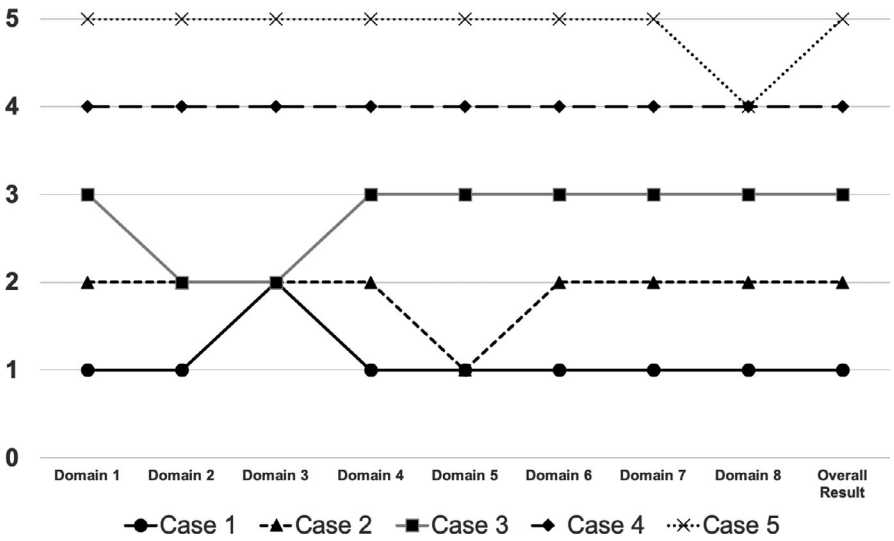

FIGURE 1 Final ratings of the index cases. The SED-S results on domain and overall level for all five index cases as consented by the 20 different raters. The overall results are clearly on the assigned level of ED; however, most cases show a slight variation within the profile

TABLE 2 Index cases 1, 2, 3, 4 and 5 in English

Cases	Description
1	Ms. K lives in a residential care facility for people with a severe to profound intellectual disability. She has been living there for about 4 months. When she reached early adulthood (around 20 years old), her parents decided it would be better for the further development of their daughter if she lived in the care facility. However, they have noticed an increase in behavioural problems during her time there, and they are worried about their daughter's well-being. They say that, during weekends, when they have their daughter at home, she wants more physical contact with them than before she moved. They were not used to such levels of cuddling. When Ms. K arrives back at the care facility after these weekend visits, she appears to be very tense. She often refuses to step out of her parents' car. In these cases, her parents accompany her to her room and quickly say goodbye; they pass her over to the caregiver of the facility who will then take care of her and who usually manages to calm her quickly. Ms. K likes to play with a sound toy and does so for long periods of time. She keeps on pushing the same button and is delighted by the ensuing flashing light and music. She also likes to lie in bed and rock her upper body back and forth in a stimulating way whilst twirling her hair and sucking her thumb. When the toy is hidden under her blanket, she specifically starts looking for it. She has fun if the caregiver hides the toy under the blanket and she finds it again. During occupational therapy, she spends a lot of time with a rubber glove with different dots. She likes to chew on the glove and stretch its fingers. She moves through the room in silence and goes straight to the material trunk where she picks the object that she prefers. Ms. K actively pursues functional contact with the important other, mainly in order to satisfy her needs. For example, she will guide the caretaker's hand to her favourite pudding when she does not want to eat goulash, and she will emphasize this by making more and more sounds. She loves to sit on the swing together with the caregiver. She puts the important other's arms around her, very closely, and she grinds her teeth dreamily whilst swinging. Her body appears relaxed in these tight situations. Sometimes when you smile at her, she smiles back. Ms. K does not seek contact with any of the other residents. It seems she is not interested in any of them. For example, in some instances, she will walk through the living area in a determined way and trip over the other residents or push them aside if they are in her way. She often gets restless and hot-tempered, not only when she is hungry or in pain but also in a normal, structured setting. In group situations (e.g. during music therapy sessions), she quickly leaves the room and heads for the quiet of her own room, where she will get into her bed, pull the blanket tightly around her body and push her face into the cushion. If she is not allowed to do that, or if she is incapable of doing that because of the tension she is experiencing, she will become very cranky, scratch herself on her arms and pull out her hair. The noises she produces, which generally sound rather pleasant, degenerate into yelling and screaming. In these situations, Ms. K. cannot be soothed verbally. The only way to calm her down is to move to a low-stimulus environment. During extended periods of agitation, relaxing baths during which she is rubbed on the back with a soft sponge also have a calming effect
2	Mr O. initially lived with his mother, with whom he has continued to spend the weekends since moving into a residential facility at the age of 16. During the day, he attends a sheltered working place for individuals with intellectual disability, where he constantly seeks the proximity of staff members and frequently wanders around looking for them. Mr O. needs help getting dressed and likes baths, sometimes splashing so enthusiastically with different parts of his body that the whole bathroom is flooded. He enjoys long walks and often goes on strolls with his favourite caretaker for hours on end, holding her by the hand and pointing excitedly at whatever catches his interest. Autumn is his favourite time of year, and he loves hearing the leaves rustle, playing with them and tearing them up. Mr O usually ignores the other residents of the home and will not return their greeting if they say hello. On other days, he behaves in an aggressive manner; when the stress reaction subsides, he looks intensely for body contact. When he does not get his way or he is faced with demands from fellow residents, it can happen that he hits, pinches or attacks them at random. At mealtimes, he sometimes tries to take food from others' plates and will get up repeatedly to help himself to more food. When it gets too noisy around him, Mr O. often starts to cry. Since he frequently becomes belligerent afterwards, the caretakers have come to regard the crying as sign of imminent aggressive behaviour. He is then accompanied to his room, where he can calm down quickly if the care takers talk to him in a quiet manner and reassure him that everything is okay. Mr O. always wants to be present when the care teams hand over to the next shift, often trying to push his way into the staff room or standing outside the glass door, waving, knocking on the glass pane or licking it with his tongue. It is extremely difficult for him to accept when caretakers tell him that they are busy or ask him to go to his room, and he can only rarely be persuaded to take even just a brief period quiet time by himself in his room. Mr O.'s favourite pastime is listening to music on his CD player, and he is able to insert CDs and select tracks by himself. He especially enjoys sharing this activity with caretakers, having them hand him a CD, which he then carefully wipes with a cloth before playing his favourite songs for them. His passion for music goes so far that, at times, he takes CDs from his fellow residents. If someone points out that the CDs belong to someone else and tries to take them away from him, he gets very upset, angrily insisting that they belong to him ("Mine!") or even starting to cry. At work, Mr O puts plastic gaskets into large plastic bags. He receives the gasket from his staff member, wipes it and throws it into the bag. On doing so, he often looks expectantly at his staff member and smiles if he or she says “And again, one more.” Mr O. particularly likes visiting the Snoezelen room (sensory therapy) because he can listen to music with the caretakers there. It is very important to him that staff members be there at night, as well. If none of them are around, he cannot sleep, becomes restless and goes out looking for them, frequently entering the rooms of his fellow residents and waking them up

(Continues)

TABLE 2 (Continued)

Cases	Description
3	Mr G. is a 33-year-old man with moderate to severe intellectual disability, who lives in a residential facility for people with intellectual disability and attends occupational therapy in a sheltered workshop during the day. He often moves around, sometimes even running off. He is very headstrong and constantly seeks attention. He also seeks extended contact with the caregivers. It is difficult for him to cope when they deal with co-clients or terminate contact with him. He frequently follows them around. As soon as caregivers come into the room, he immediately seeks—often physical—contact with them. Mr G. has difficulty occupying himself or engaging in activities on his own. Only when playing with his favourite toy building brick can he be on his own for a short time. For the most part, the caregivers have to stay by his side and provide active support and encouragement. He likes to talk with the caregivers about what he is doing at that moment, what he is dealing with during the day, or what he has eaten. He often enquires about the same things several times, for example, if they are really going to the swimming pool as planned. When caregivers Sandra or Phillip are working at the residential facility, Mr G seems more relaxed. These are his favourite caregivers, and he prefers to be with them more than with other caregivers. When caregivers are interacting with someone else, he often butts in and tries to get their attention for himself. Even if the caregivers make a phone call, for example, he disturbs them in order to seek their attention. Often, on these occasions, he looks around the corner, waves and says hi, before hiding and then looking around the corner and greeting them again. Mr G. frequently gets into disputes with other residents of the home. For example, he insists on using his own rules when playing board games with other residents and becomes agitated and shouts "No! You have to do it this way!" or "It's my turn!". He sometimes takes food and other things from his fellow residents. When confronted with his behaviour, he says "No! I certainly didn't do that!" When he drops things and cannot immediately find them, he forgets about them quickly. Mr G. likes to join in with a creativity course—even if the group often argues over several painting materials. He always draws a lot of pictures, but then he loses interest and leaves his pictures in the room at the end of the course. He loves pens and is fascinated by their composition. He enjoys taking these pens apart and is often not able to put the different parts back together again. He gets angry very quickly and protests vehemently when the caregivers set boundaries for him. However, the caregivers mostly succeed in changing his negative mood by offering another activity. Mr G. needs support with physical care, so the caregivers help him. In these situations, conflicts often arise because Mr G. wants to do everything on his own, even if it takes a long time or he is at risk of destroying his clothes. He always gets very angry, for example, when the caregiver wants him to put on a long-sleeved shirt because it is cold outside, but he insists on wearing a certain T-shirt. Once, Mr G. was so angry that he threw himself onto the ground because the caregivers wanted to prevent him from hurting himself when trying to open a jar of cream with a nail file. The members of Mr G.'s residential group travel to the same destination for a holiday every year, and during these holidays, Mr G. requires constant attention from trusted caregivers. He shows no interest in venturing outside the familiar environment of the holiday accommodation to explore the surroundings on his own, preferring to stay close to the caregivers. He wants to be reassured frequently that the caregivers will stay with him and not go away. He needs the caregivers to stay by his side to offer encouragement and hold his hand on outings. If he is left alone in these situations, he becomes afraid and tense and then verbalizes that fear by saying that he is scared
4	Mr D. is a 33-year-old man with borderline intellectual disability (IQ between 70 and 85). He lives in an apartment directly next to a group home where 24-hr care is provided. He makes decisions on practical issues about the here and now in consultation with his mother or personal caregiver. He gladly shares important daily activities with well-known caregivers. The caregivers call him every day at set times. He does not always answer the phone, for example, when he is with his friends. In talks with authorities, for example, concerning his finances, it is necessary that well-known caregivers accompany him. Mr D. is a lean, tall man, with tattoos on his arms. Generally, people describe him as being tired based on his facial expression and posture. He often wears a baseball cap or hooded coat, as well as a “cool” black jacket, and clothes with a “Real Madrid” logo on them. Mr D. enjoys looking tough, independent and nonchalant. He is proud of his football team posters of “Real Madrid,” posters of separate players, and the statue of “Real Madrid” inside his apartment. His big hero is Cristiano Ronaldo, who is also 33 years old. Mr D. fantasizes about playing in the Football Arena against top European clubs, during which he can become lost in his imagination. His caregiver tried to involve him in a soccer team, but this did not really work. Mr D. always felt discriminated against when his team members did not pass the ball to him, and he would leave the playing field. Neighbours and friends ask him to do small jobs, which vary in length. However, these jobs are often "black-market” jobs and without a contract. Mr D. is very handy: he does a lot of work to make his house more beautiful, for example, by painting the Real Madrid coat of arms on a cupboard or refurbishing second-hand items. He works with the support of a job coach in road construction or in the renovation of houses. His work supervisor keeps an eye on both his work and his cooperation with colleagues. Mr D. accepts his colleagues but prefers to have his own tasks to do rather than working closely together with them. Mr D. travels by public transport or by bike on well-known routes throughout the city. He avoids using his own initiative in taking unknown routes, as he does not know what to do in these situations. Currently, Mr D. is in a relationship with his girlfriend of several weeks. They like to do nice things together (such as drink a beer in the nearby pub or watch movies together). However, they often quarrel and need the caregivers' support and guidance to reflect on the situation. They both have difficulty in understanding each other well. Caregivers teach them to give words to their feelings and to take the other's perspective. During weekends, Mr D. likes to stay with his girlfriend and her parents at their home.

(Continues)

TABLE 2 (Continued)

Cases	Description
	Mr D. is jealous when other men look at his girlfriend. He is afraid his girlfriend will leave him for another man. Sometimes, this leads to conflict when another man gets closer to her or talks to her. His girlfriend and bystanders must stop him from bursting out in aggression or fighting. In retrospect, when Mr D. reacts in this way, he is ashamed about what has happened; he feels guilty and wants to make up very quickly. Mr D. often cares for his mother when she is not feeling well or is ill. He always says that this is what a family is about and that helping each other has been a rule at home since he was a little boy. Furthermore, he plays with his younger (step) brothers. He takes over tasks such as doing the shopping and household work (e.g. vacuuming and washing the laundry). Mr D. is still in touch with two friends from school, which he left 13 years ago. Some of his current friends (also fans of Real Madrid) have a higher IQ, and some are several years younger. With his friends, he likes to play computer games like FIFA. They also watch the Real Madrid football games on the television together. He is often too generous with money and goods to others. He reacts in this way because he wants others to like him. Mr D. shows little emotion in his face and body: he seems detached except for when he is angry. He shows empathy towards his mother and girlfriend when they need him. If he suspects that someone is angry with him, such as his work supervisor, he will avoid contact. He is ashamed and afraid to fail. When he feels familiar with the caregiver, he can indicate that he feels sad. He can also indicate when he is afraid that unpleasant things could happen to him, his girlfriend or his family. Mr D. is a silent man. His favourite topics for discussion are Real Madrid, gaming and his family. When others cross him, he gets angry. In contact with strangers, he is accessible, but he prefers to chat with strangers in the presence of a trusted other person. Mr D. sometimes has a bad temper and shows verbal aggression, but he can also show physical aggression. He has fought with several people including his stepfather. If it does not go well with his girlfriend or mother, he becomes very irritable and gets angry. When his caregivers support him, he can describe (often afterwards) why he was angry. Once, his girlfriend got a new haircut, and he told her very directly that she "looked like shit," which led to a conflict between the two. Later, after having spoken to his caregiver about it, he apologized to her and urged his caregiver to help him send her flowers. He is only aggressive to his caregivers if he disagrees with decisions or appointments made
5	Mr S. is a 24-year-old with a mild intellectual disability who lives in a partially assisted living community. He was previously employed in a sheltered workplace but lost his job because of aggressive behaviour in the form of damaging property and verbal abuse. His aggressive behaviour was the main reason which prompted the decision for him to undergo outpatient treatment. The young man who introduced himself in the outpatient department is significantly overweight but well-groomed and neatly dressed in clothes emblazoned with alcohol brand logos and politically provocative slogans. He proudly points out that his friends thought the jacket was really "cool." He appears friendly, but reticent. He asserts that he would like to work but not too early in the morning. He reported not being willing to accept it quietly when someone provokes him or one of his friends. At home, Mr S. rarely takes part in joint activities and spends most of his time playing video games with his friends or strikes out to obtain new video games. Regularly, Mr S. challenges the caregivers to play video games with him. Thereby, it is important to him to compete with the staff and to get recognition for his playing abilities. He maintains friendships with a group of men of the same age outside his residential group whom the caregivers believe to be right-wing extremists. This group is very important to him. He never misses "get togethers" and also initiates these himself. These get togethers take place in different locations depending on what is possible at the time. He and his friends play video games, but they also get into physical fights from time to time. Mr S. regards these brawls as just a game and often talks proudly about how he has beaten others at arm wrestling. Mr S. has a skin disease and often says that no girl would ever want him because they all think him fat and unclean. He says this makes him sad because even if he is overweight and has ugly skin, he still has a good heart and would make a good and reliable boyfriend. When his caregiver tries to talk to him about what having a girlfriend would mean for him, he does not respond and changes the topic. On other occasions, Mr S. can show hostile behaviour towards the staff, which then gives rise to tensions and conflicts within his residential community: "They don't listen to me anyway. If I have a problem, I will go to my aunt or to the staff from my former workplace!" Then, he verbally threatens the staff as well as other residents. After cooling down in his room or during a stroll, he is able to express that he is feeling unfairly treated, and he can develop strategies to react less violently the next time. Mr S. had voted in favour of cleaning a particularly dirty kitchen together with his housemates. Together with the other residents, he subsequently cleared out the dishes and wiped down the cupboards in an appropriate and cooperative manner. He seemed cheerful and relaxed whilst they worked, joking around with the others, telling them that he was "in a very good mood." He told the caregivers what he was doing and was very pleased with them praising him for cleaning the top of the kitchen cabinets better than his housemates. But when he got a call on his cell phone, he wanted to drop everything and leave right away to meet his friend because this one had "real problems" at that time. When one of his fellow group members appealed to him to finish his work first, he shouted, "You don't have to tell me what to do! This is all just a bunch of bullshit for total morons, anyway!" and stormed out. Mr S. doesn't want to invite his friends to visit him in his residential home because they would see that he lives with "morons," and he is worried about what his friends would think of him

factor for the abilities of a person to adapt and adjust to daily life challenges (Sappok et al., 2014). Despite the high correlation between IDD and ED, discrepancies between cognitive and emotional development can be found (Böhm et al., 2018). Therefore, as proposed in the guidelines of the National Association of the Dually Diagnosed (NADD), the level of ED should be ascertained in the context of an assessment of problem behaviour in people with IDD (Gardner, Došen, Griffiths, & King, 2006).

The clinical usefulness of an assessment instrument rises and falls with its psychometric properties, especially its clinical significance

(Cicchetti et al., 2011). The importance of reliable instruments is evident in the ground-breaking work of Lord et al. (2012), in which they demonstrated significant site differences in the clinical diagnosis of autism spectrum disorders despite similar scores on standardized measures. An important factor to ensure the reliability of a measure is the writing of a manual to explicitly describe the framework and application method, as has been done for the SED-S in German (Sappok et al., 2018) and Dutch (Morisse et al., 2017). The structured development of representative clinical cases, which can be used in training for the application of the SED-S, is another step towards a reliable measure. However, we are aware of the need to develop standardized training manuals and reliability assessments of the assessors to ensure proper application of the scale. Moreover, continuous supervision and calibration of the assessors are pivotal to consistently maintain the reliability and validity of results (Kamp-Becker et al., 2018).

Cultural differences cannot be ruled out when judging other people's behaviour. Differences in the scoring of standardized instruments occur and are a constant challenge for researchers but even more so for clinicians. In a cross-cultural study, the validity of the *Social Communication Questionnaire*, a widely used and manualized instrument for the assessment of autism spectrum disorders, was evaluated in adults with IDD (Sappok, Brooks, Heinrich, McCarthy, & Underwood, 2017). Among other variables, such as level of IDD and gender, the sum scores were highly dependent on the study site, with Germany scoring higher than the United States of America, which, in turn, scored significantly higher than the United Kingdom. These differences were still visible when the data were corrected for other variables affecting the sum score. The authors discussed language and cultural differences, but differences in the method of administration and the reference criterion were also presumed. Future research may address the impact of socio-cultural factors on the assessment of the level of ED. Overall, as can be seen by the good to excellent ICC values, the differences between the different raters are not considered to be significant.

Certain limitations need to be considered when interpreting the results. The high agreement between the raters may be caused by the high level of experience on the one hand, and the numbers of meetings and clinical case discussions on the other. Moreover, despite being anonymized and revised for didactic reasons, 11 of the 20 coders were present when the index cases were first rated in the original meeting. However, our results did not show larger variation in the ratings of the nine raters who had not been involved in the development of the cases compared with those who had been involved. This can be seen as a good indicator for the clear and specific case descriptions. Finally, the reference to the client's level of ID may have influenced the readers' ratings consciously or unconsciously. In future case vignettes, more detailed descriptions about daily living skills and behaviours and omission of the level of ID may reduce the bias. Further assessment of the scale reliability needs to be carried out in clinical practice by adapting general instructions to a real structured interview, which is rather different from an artificially written case description.

In conclusion, to improve the quality of application of the SED-S and to reduce the number of discrepancies between raters, a multi-cultural approach was used to develop index cases for each level of ED. Assessment using these five index cases may support researchers and clinicians worldwide to apply and score the SED-S in a uniform way. This may reduce the variability of the results and their dependence on the assessor's characteristics and opinion.

ACKNOWLEDGMENTS

We would thank the parents and the individuals on which the index cases are based for providing the NEED group with the video material. Moreover, we would also like to thank the NEED members who were involved in the development of the index cases and the ratings.

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How to cite this article: Sappok T, Došen A, Zepperitz S, et al. Standardizing the assessment of emotional development in adults with intellectual and developmental disability. *J Appl Res Intellect Disabil*. 2020;33:542–551. https://doi.org/10.1111/jar.12697