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JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/jir.12556

VOLUME 63 PART 1 pp 40–48 JANUARY 2019

Classification of intellectual disability according to domains of adaptive functioning and between-domains discrepancy in adults with epilepsy

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Abstract

Background In the Diagnostic and Statistical Manual of Mental Disorders–Fifth edition (DSM-5), the diagnostic criteria of intellectual disability (ID) include three domains of adaptive deficits: the conceptual, social and practical. Substantial intra-individual differences between domains can be considered an ID domain discrepancy.
Method We explored the associations between ID domains, discrepancies and epilepsy in 189 adults (mean age = 47.9; SD = 15.6). Each DSM-5 ID domain was assessed separately, using subscales of the Vineland II for the social and practical domains, and psychological instruments, including intelligence tests, for the conceptual domain. A set of standardised criteria is proposed to identify an ID domain discrepancy.
Results An ID domain discrepancy seemed to be present in about one-third of subjects and was particularly present in subjects with moderate ID (53.4%). Impairment in the social domain was most often the reason for the discrepancy. The presence of a discrepancy was significantly related to a focal (localised) epilepsy type (OR = 2.3, $P = .028$) and a mixed seizure type (OR = 1.4, $P = .009$). Epilepsy characteristics that are indicative of a more severe and refractory epilepsy, including various seizure types, a high seizure frequency, a combined epilepsy type (both focal and generalised epilepsy) and an early age at onset, were significantly related to more severe impairments in conceptual, social and practical adaptive behaviour (all P values $<.01$).
Conclusions With a substantial proportion of the subjects who had both ID and epilepsy with an ID discrepancy, professionals should be aware of this and take all domains of ID into account when studying or working with this vulnerable population.

Keywords assessment, developmental disability, diagnosis, DSM-5, seizures

Background

The diagnostic criteria of intellectual disability (ID) have been revised in the Diagnostic and Statistical Manual of Mental Disorders–Fifth edition (DSM-5;

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American Psychiatric Association 2013). One of the most prominent changes is the shift towards a tripartite model in which the severity of deficits, in terms of adaptive functioning, is to be addressed on three domains: conceptual, social and practical. The conceptual domain refers to skills in reading, writing, mathematics, executive functioning, memory and knowledge; the social domain includes interpersonal communication skills, empathy, social judgement, emotional regulation and the ability to make and retain friendships; the practical domain refers to personal care, organising school, work and domestic tasks, and money management (American Psychiatric Association 2013).

The new criteria require professionals to attribute a severity indication of deficits in each domain of adaptive functioning, that is, mild, moderate, severe or profound deficits. As a consequence, the introduction of the DSM-5 has or will have implications for the diagnostic process, as each domain should be comprehensively assessed both clinically and using standardised instruments (American Psychiatric Association 2013). In the past, results from intelligence tests did have a prominent role in diagnostics of ID according to DSM-IV (American Psychiatric Association, 2000); these tests, however, were essentially related to only one of the three domains: the conceptual domain (Schalock 1999; American Psychiatric Association 2013). The focus of the ID diagnostic criteria has now shifted towards assessing adaptive functioning by using standardised measures, such as the Vineland Adaptive Behavior Scales (Sparrow *et al.* 2005; Sparrow *et al.* 2016), the Adaptive Behavior Assessment System (Harrison and Oakland 2003; Harrison and Oakland 2015) and the Scales of Independent Behavior-Revised (Bruininks *et al.* 1996).

The potential advantage of assessing the three DSM-5 domains of adaptive functioning separately is that one obtains a more accurate representation of the functioning of the individual. The new classification reveals an opportunity to define a concept of ID domain discrepancy in which one domain is particularly more deficient than another. Some instruments that measure adaptive behaviour, such as the Vineland-II, allow for between-domain comparisons that indicate whether standard scores between domains are significantly different. A person could, for example, demonstrate conceptual skills particularly worse than the social skills. With no other studies that have yet addressed ID discrepancies, increasing knowledge with respect to the relation between the three domains is relevant for both clinical care and research in this vulnerable population.

Deficits in specific domains of adaptive functioning might be related to impairments of specific brain structures, impaired neuronal networks or to co-morbidity. For example, persons with autism spectrum disorder have poorer socialisation skills compared with other domains (Kanne *et al.* 2011), and traumatic brain injury, often affecting the prefrontal regions, can result in persistent executive dysfunction (Hartikainen *et al.* 2010). Among people with ID, epilepsy is a particularly common co-morbidity; it can be severe and have a pervasive impact (Bowley and Kerr 2000; Kerr *et al.* 2014; Robertson *et al.* 2015). Epilepsy is conceptually defined as a brain disease characterised by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological and social consequences of this condition. Epileptic seizures imply the transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain (Fisher *et al.* 2005). An operational clinical definition of epilepsy is provided by Fisher *et al.* (2014). People with chronic epilepsy are at risk of altered brain development and accelerated ageing, which can result in cognitive deficits or deterioration (Lin *et al.* 2012; Breuer *et al.* 2016). In addition, some epilepsies have been linked to impaired practical adaptive behaviour, such as daily living skills (Berg *et al.* 2004; McGrother *et al.* 2006). One might speculate that the long-term impact of epileptic seizures might result in impairment of specific aspects of adaptive functioning, depending on the brain area affected by the seizures.

In the present study, we focus on three domains of ID in a clinical sample of adults with chronic epilepsy. The primary aims were to introduce a method to identify a between-domain discrepancy, to describe the point prevalence in this specific sample and to explore the associations between a discrepancy and epilepsy characteristics. The secondary aim was to examine associations between

epilepsy characteristics and level of ID of each domain of adaptive functioning.

Methods

Participants and procedure

This cross-sectional study was conducted within a tertiary epilepsy centre with both inpatient and outpatient care facilities in The Netherlands. All individuals who met the following criteria were invited for the study:

- age ≥18 years;
- diagnosis of epilepsy according to the clinical definition by Fisher *et al.* (2014);
- previous diagnosis of ID or current adaptive functioning at level of ID as evaluated by the individual's health care psychologist.

A total of 240 individuals were invited for the study, of whom 189 provided consent for the study (inclusion rate: 78.8%). The consent was provided by legal guardians in case individuals did not have the capacity, by individuals themselves if they were capacitated, or by both the individual and their legal guardian if the individual was capacitated but also had a legal guardian. Individuals who participated were significantly younger (mean difference = 6.04 years, $P = .015$) than non-participants and were using psychotropic medication less frequently (14.0% vs. 41.3%, respectively, $P < .001$). Participants did not differ from non-participants with respect to gender or level of ID.

This study was approved by the local ethical committee of Kempenhaeghe Epilepsy Centre (No. 15.01). The subjects could withdraw from the study at any time.

Instruments and procedure

Information with regard to demographics and epilepsy was collected from the subject's medical records. This included information about age, sex, age at epilepsy onset, daily use of anti-epileptic drugs, epilepsy type and seizure type and frequency in the last year. The epilepsy type was classified according to the guidelines of the International League against Epilepsy (Scheffer *et al.* 2017), and for seizure types, the classification system of Lüders *et al.* (1998) was applied.

The assessment of classification level of ID was based on the three domains of adaptive deficits as described in DSM-5 (American Psychiatric Association 2013): conceptual, social and practical. These domains were assessed separately. The selection of instruments was based on psychometric qualities, feasibility, international use and availability in Dutch language.

Social and practical domain

The social and practical domains were addressed by the Vineland Adaptive Behavior Scales, second edition, Expanded Interview Form version (Vineland-II; Sparrow *et al.* 2005; Dutch translation by Dijkxhoorn and Verhaar, 2012), a clinical instrument to assess adaptive behaviour. For the purpose of this study, only the Daily Living Skills (DLS) and Socialisation subscales were administered by means of a semi-structured interview with a professional caregiver who is familiar with the subject for at least 1 year. The scoring procedure was performed according to the manual, resulting in an age-corrected standard score for both subscales (M = 100 and SD = 15), representing the social and practical domains.

Conceptual domain

As the Vineland-II has no subscale directly in accordance with conceptual functioning, the conceptual domain was assessed by other instruments. As many instruments are not suitable for all levels of ID, this assessment was adjusted to the subject's expected level of functioning. The instrument of choice was discussed with the subject's health care psychologist prior to administration. As the intelligence quotient (IQ) seems to be largely representative of the conceptual domain, this was the first-choice measure. The (full scale) IQ was obtained either from the subject's medical records, if administered within the past 2 years, or by administering the 4-subtest short form (SF) of the Wechsler Adult Intelligence Scale–Fourth Edition (WAIS-IV-SF). This WAIS-IV-SF is a short form validated among people with neurological disorders and impaired intellectual functioning (Van Ool *et al.* 2018). In cases of lower expected

conceptual functioning, the Picture Peabody Vocabulary Test–Third edition (PPVT-III; Dunn & Dunn 1997) was used, which results in an estimation of the developmental age. The PPVT-III is a measure of receptive vocabulary and is considered a valid screening tool for global cognitive functioning (Castellino *et al.* 2011; Yin Foo *et al.* 2013).

If neither the WAIS-IV-SF nor PPVT-III were suitable and no psychological reports on intellectual functioning were available, an expert opinion about the level of conceptual functioning was formulated based on DSM-5 criteria (American Psychiatric Association 2013). This expert opinion was provided by a qualified health care psychologist who treated the person for at least 1 year. This procedure was also applied in cases where the legal representative did not give consent for the assessment of conceptual measures (n = 3) or if subjects expressed signs of objection during the individual assessment, after which the assessment was aborted (n = 2).

Level of intellectual disability and intellectual disability domain discrepancy

The results on each domain were converted into a classification of mild, moderate, severe or profound deficits. Internationally applied cut-off points, described by DSM-IV, the International Statistical Classification of Diseases–tenth edition and Vineland II, were retained, all using cut-off points of 70–50/55 for mild deficits, 50/55–35/40 for moderate deficits, 35/40–20/25 for severe deficits and below 20/25 for profound deficits (World Health Organization 2010; Sparrow *et al.* 2005; American Psychiatric Association, 1994). The lower values were applied, and all classifications were validated by the subject's health care psychologist.

An ID profile was considered as discrepant when there was a substantial difference in level of adaptive functioning between two DSM-5 domains, indicating that one domain is considerably more or less deficient than the other(s). As different measures were used to assess the domains, multiple criteria could be applied to determine whether a discrepancy was present. An ID domain discrepancy was attributed if one of the following criteria was met:

- Social versus practical domain: a difference between the Socialisation and DLS standard scores with significance level of .01, according to the Vineland II manual (Sparrow *et al.* 2005)
- Social or practical domain versus conceptual domain:
    - a difference of at least 15 points (=1 SD) between the Short Form IQ of the WAIS-IV-SF and the Socialisation or DLS standard score; or
    - if the conceptual domain was determined by the PPVT-III or expert opinion: a difference of at least one complete classification level between the conceptual domain and the social or practical domain.

Statistical analyses

Associations between epilepsy and ID domain discrepancy were explored using logistic regression analysis. The backwards stepwise method was applied to remove nonsignificant factors from the model, that is, $P > .15$, based on Wald's test. The associations between epilepsy characteristics and domain or average level of ID and ID domain discrepancy were explored using IBM SPSS Statistics version 24. For associations between level of ID and epilepsy characteristics, chi-square tests were performed for categorical data and nonparametric tests were conducted for continuous data (including Kruskal–Wallis and Mann–Whitney U) as the continuous data did not meet the assumption of normal distribution. Subjects with a severe or profound ID classification were combined into one subgroup in the analyses. Results were considered significant if $\alpha < .05$.

Results

Sample characteristics

A total of 189 subjects met our inclusion criteria. See Table 1 for a complete overview of clinical characteristics. The majority of subjects were inpatients (76.2%); the others lived in community settings. The mean age was 47.9 years (SD = 15.6; range 18.3–85.9 years) and 58.7% were male. The epilepsy originated in childhood in more than half of subjects (54.4%). Most subjects had focal epilepsy or a combination of focal and generalised epilepsy (41.3% and 44.4%, respectively), with a seizure frequency of at least once a week (55.5%). Nearly all

Table 1 Clinical characteristics of the study sample ($N = 189$)

Characteristics	Values
Age at onset of epilepsy (years)	*Mdn* = 2.0, *IQR* = 0–5.5, range 0–53
Infancy (<1 year)	32.8%
Childhood (1–12 years)	54.0%
Adolescence (12–18 years)	10.1%
Adulthood (18+ years)	3.2%
Epilepsy type	
Generalised	10.6%
Focal	41.3%
Both generalised and focal	44.4%
Unknown	3.7%
Number of seizure types (semiology)	*Mdn* = 3.0, *IQR* = 1–4, range 0–8
Seizure frequency (last year)	*Mdn* = 70.0, *IQR* = 11.5–153.0, range 0–1206
Seizure-free	12.7%
Yearly	12.2%
Monthly	19.6%
Weekly	43.9%
Daily	11.6%
Daily use of anti-epileptic drugs	*Mdn* = 3.0, *IQR* = 2.5–4.0, range 0–6
0	0.5%
1	7.9%
2	16.4%
3+	75.1%

IQR, interquartile range; Mdn, median.

subjects were using anti-epileptic drugs (99.5%) and 41.5% were prescribed psychotropic medication on a daily basis.

The average level of ID varied from mild to profound deficits; most subjects were classified as having moderate (30.7%) or severe (29.1%) deficits.

Intellectual disability domain discrepancy

An ID domain discrepancy – a substantial difference in level of adaptive functioning between two domains of adaptive functioning – was present in 32.8% of subjects. An ID domain discrepancy was significantly more often present in subjects with moderate ID (53.4%) and significantly less often present in subjects with a profound level of ID (5.3%; $\chi^2(3) = 24.7$, $P < .001$; Table 2). With respect to the three adaptive domains, it appeared that an ID domain discrepancy was most often characterised by a more impaired social or practical domain (in 59.7% and 38.7% of cases, respectively), and less often by a more impaired conceptual domain (16.2% of cases). Thus, the social adaptive skills were relatively often particularly poorer than the subject's practical and/or conceptual adaptive skills. Seven subjects had two out of three adaptive domains being particularly more impaired than the other.

Associations between intellectual disability domain discrepancy and epilepsy

The associations between epilepsy characteristics and ID domain discrepancy, taking the average level of ID into account, were explored using logistic regression. A stepwise backward regression procedure was applied to obtain a parsimonious model (Table 3). Predictors were stepwise removed according to their odds ratio, starting with the lowest associations. The

Table 2 Level of ID and ID domain discrepancy

Level of ID	Conceptual domain (%)	Social domain (%)	Practical domain (%)	Overall level of ID (%)	ID domain discrepancy present (per overall level of ID) (%)
Mild	17.5	17.5	21.2	*n* = 38 (20.1)	34.2
Moderate	39.2	24.9	29.6	*n* = 58 (30.7)	53.4
Severe	23.3	36.0	30.2	*n* = 55 (29.1)	29.1
Profound	20.1	21.7	19.0	n = 38 (20.1)	5.3
Total sample ($N = 189$)					32.8

ID, intellectual disability.

Table 3 Factors associated with ID domain discrepancy using stepwise backward logistic regression

Model parameters	Predictors	Odds ratio	95% CI
Adjusted model			
$\chi^2(4) = 32.11$***	Mild level of ID	3.64*	1.30–10.25
Nagelkerke $R^2 = .226$	Moderate level of ID	8.00***	3.22–19.70
	Number of seizure types	1.35**	
	Focal epilepsy type	2.33*	1.08–1.68 1.10–4.94

*$P < .05$.
**$P < 0.01$.
***$P < .001$.
CI, confidence interval; ID, intellectual disability.

final model, including the level of ID, number of seizure types and epilepsy type, is significantly associated to the presence of an ID domain discrepancy (model: $\chi^2(4) = 32.1$, $P < .001$). While adjusting for level of ID, a higher number of seizure types and a diagnosis of a focal epilepsy type significantly increased the likelihood of having an ID domain discrepancy (OR = 1.4, 95% CI = 1.1–1.7, $P = .009$; OR = 2.3, 95% CI = 1.1–4.9, $P = .028$, respectively). In addition, both a mild or moderate level of ID increase the likelihood of having an ID domain discrepancy, with an odds ratio of 3.6 (95% CI = 1.3–10.3, $P = .014$) and 8.0 (95% CI = 3.2–19.7, $P < .001$), respectively.

Associations between levels of adaptive deficits and epilepsy

Analyses of direct associations between epilepsy characteristics and the average level of ID revealed that a more severe level of ID were significantly associated with an earlier age at epilepsy onset and a higher number of seizure types and seizure frequency (all P values <.001, Table 4). There was also a significant association between the level of ID and the epilepsy type. Subjects with a severe–profound level of ID had more often a combined generalised and focal epilepsy type and less often a focal epilepsy type only ($\chi^2(4) = 13.5$, $P = .009$, Table 4). There was no association between the level of ID and daily use of anti-epileptic drugs.

Post hoc Mann–Whitney U tests showed that significant differences were particularly present between subjects with a mild level of ID and subjects with a severe–profound level of ID (all P values <.001) and between subjects with a moderate level of ID and severe–profound level of ID (all P values <.001). When comparing subjects with a mild level of ID and those with a moderate level of ID, only the age of onset was significantly different (median = 5.0 years vs. 3.0 years, respectively, $P = .007$).

With regard to each of the three DSM-5 domains, conceptual, social and practical adaptive functioning, Kruskal–Wallis and chi-square tests showed a similar pattern of significant associations compared with the average level of ID. For each domain, a more severe level of deficits was significantly related to an earlier age at epilepsy onset (all P values <.001), more often a combined epilepsy type (P values = .019–.009), a higher number of seizure types (all P values <.001) and a higher seizure frequency (P values = .002–<.001).

Discussion

In the present study, the associations between epilepsy characteristics and the revised DSM-5 classification of ID, in terms of three domains of adaptive functioning, were explored in a clinical sample of 189 adults with both epilepsy and ID. Each of the three domains of adaptive functioning (conceptual, social and practical) was addressed separately, as well as an overall measure of ID. We introduced a set of criteria for identifying a discrepancy between DSM-5 domains in an ID profile and investigated associations between epilepsy and ID discrepancies.

Nearly one-third of our sample demonstrated a discrepancy in their ID profile. Impairment in the social domain was most often the reason for the discrepancy, indicating that the social skills were more impaired than practical and/or conceptual adaptive behaviour. This ID profile might be associated with the high prevalence of autism and autistic-like features among people with ID and/or epilepsy (e.g. Berg and Plioplys 2012), which is characterised by deficiencies in social communication and social interactions (American Psychiatric Association 2013). In addition, social impairments may also relate to the lack of opportunity to develop

Table 4 Associations between epilepsy characteristics and average level of ID

	Overall level of ID			
	Mild	**Moderate**	**Severe–profound**	
Epilepsy characteristics	**Mdn, [IQR]**	**Mdn, [IQR]**	**Mdn, [IQR]**	**Statistic**
Age at onset of epilepsy	5.0 [2.8–13.0]	3.0 [0.8–6.0]	1.0 [0.0–3.5]	H (2) = 25.07***
Number of seizure types	2.0 [0.0–3.0]	2.0 [1.0–3.0]	4.0 [3.0–5.0]	H (2) = 42.04***
Seizure frequency	18.0 [2.0–56.0]	58.5 [4.3–127.3]	106.0 [35.0–272.0]	H (2) = 24.59***
Daily use of anti-epileptic drugs	3.0 [3.0–4.0]	3.0 [2.0–4.0]	3.0 [2.0–4.0]	H (2) = 1.20 (P = .549)
Epilepsy type				$\chi^2(4) = 13.48$**
Generalised only	4 (10.5%)	8 (15.1%)	8 (8.8%)	
Focal only	22 (57.9%)	27 (50.9%)	29 (31.9%)	
Both generalised and focal	12 (31.6%)	29 (31.9%)	54 (59.3%)	

*$P < .05$.
**$P < 0.01$.
***$P < .001$.
ID, intellectual disability; IQR, interquartile range; Mdn, median.

such skills, due to the combination of having an ID as well as living in the more protective and less demanding environment of the residential setting when compared with living in the community. Although no other studies have yet been published regarding ID discrepancies with respect to the three domains of adaptive functioning as far as we are aware, this proportion seems clinically relevant. Addressing an ID domain discrepancy in daily clinical practice could, for example, have implications for the treatment strategies to meet both the strengths and needs of the individual.

An ID discrepancy was particularly present in those with a moderate level of ID (53%) and less often in individuals with a profound level of ID (5.3%). This might be related to the broader spectrum of self-care skills and (social) activities in which individuals with a moderate ID are regularly engaged, by which personal specific strengths and needs become more visible. In addition, a lower rate of ID discrepancies could be explained by a floor effect in those with a profound level of ID, as this is the lowest level. While controlling for the level of ID, the odds of having an ID discrepancy was significantly associated with a focal epilepsy type (i.e. a form of epilepsy that originates from an area on one side of the brain) and, regarding types of seizures, with a mixed seizure type. It is tentative to speculate that the reason for the increased ID discrepancy in patients with a focal form of epilepsy is explained by a focal lesion causing both the epilepsy and ID. As a mixed seizure type is more often observed in a (multi)focal form of epilepsy, this might also explain the increased ID discrepancy in patients with these types of seizures. In addition, a methodological confounding effect should be considered as well, as the probability of having focal seizures increases with a higher number of different seizure types. To further clarify the working mechanisms, future research should focus on associations between specific brain areas that are regularly affected by epilepsy, for example, the temporal lobe, and adaptive functioning, using neuroimaging.

A secondary finding was that a refractory and more severe epilepsy, including a higher seizure frequency, mixed seizure types and an earlier age at epilepsy onset, was significantly associated with a more severe overall ID. These characteristics were also related to a more severe impairment of each of the domains: conceptual, social and practical adaptive behaviour. Also, having a form of both generalised and focal (localised) epilepsy was associated with a more severe overall ID. This subgroup might reflect a large number of patients with epileptic encephalopathy, which is often accompanied by developmental slowing or regression (e.g. McTague *et al.* 2015). Although it is

well known that the prevalence of epilepsy increases with the severity of ID (Robertson *et al.* 2015), the increase in epilepsy severity among people with severe ID is less well documented. Causal inferences cannot be made, as both severe epilepsy and ID can reflect a highly affected brain or brain networks, or have the same underlying cause, such as genetically determined syndromes (e.g. Leung and Ring 2013). Longitudinal research of epilepsy characteristics is needed to clarify the long-term impact on aspects of cognitive and adaptive functioning, while taking into account the aetiology of epilepsy.

The present study has some limitations. Although the subjects came from one tertiary care facility, which increases homogeneity and reliability of data sampling, the majority lived at a residential care facility. Therefore, our findings require validation in a more representative sample of persons with epilepsy and ID, preferably with a control group without epilepsy when studying ID domain discrepancies. In addition, only instruments available in the Dutch language could be used. The Adaptive Behavior Assessment System–Third Edition (Harrison and Oakland 2015) and the Diagnostic Adaptive Behavior Scale, which is under development by the American Association on Intellectual and Developmental Disabilities, are promising instruments that match the ID domain structure of DSM-5. These have, however, not yet been adapted to the Dutch language; our data might, therefore, have a lower content validity.

This exploratory study is, to our knowledge, the first to specifically focus on each domain of ID and to derive possible ID domain discrepancy, which might have great implications for clinical practice and research. With nearly one-third of individuals with epilepsy having an ID domain discrepancy emphasises the relevance of this concept and the importance of assessing each domain of adaptive functioning. In order to minimise the risk of overestimating or underestimating an individual, it is important for professionals to take into account the full spectrum of ID and to be aware of the possibility of an ID domain discrepancy. Also, regular follow-up of both epilepsy and ID is recommended, as treatment and services should take into account both epilepsy and ID in personal plans and evaluations to improve the social care and health of this population (Kerr *et al.* 2014).

Acknowledgement

This research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors.

Conflict of interest

None of the authors has any conflict of interest to disclose.

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Accepted 27 September 2018