

# Intellectual disability and psychiatric disorders: more than a dual diagnosis ...

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## Summary

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**Background:** Despite the difficulties associated with establishing a diagnosis of a mental illness in persons with intellectual disability, most authors agree to say that those persons are at high risk of developing comorbid serious mental illness but the prevalence of psychiatric disorders in this population varies widely. The main reason for this variation lies in the difficulty to diagnose intellectual disability and psychiatric disorders at the same time. The aim of the present study is to investigate the association between severity of intellectual disability and prevalence of psychiatric and somatic disorders in an adult population with intellectual disability treated in the Psychiatric Unit of Mental Development (UPDM) in Geneva, Switzerland.

**Methods:** The present study is based on the analysis of the medical record of all ambulatory patients of the UPDM treated in March 2008. This population presents at least a dual diagnosis of intellectual disability associated with psychiatric disorders.

**Results:** Data show that 59.1% of the total sample has behavioural disorders and this percentage increases with severity of intellectual disability since it is higher in persons with severe and profound intellectual disability (79.7%). Furthermore, 48.2% of our sample has psychiatric disorders and this percentage is higher for persons with mild intellectual disability (59.5%). The most frequent

psychiatric diagnosis associated to intellectual disability are pervasive developmental disorders (27.4%) and its prevalence is higher in the severe and profound intellectual disability level (66.1%), while schizophrenia and disorders of adult personality are significantly more frequent in the mild intellectual disability level (20.4% and 23.0% respectively). Furthermore, 31% of the sample have somatic disorders and its prevalence is higher in persons with severe and profound intellectual disability (55.9%). Considering the total prevalence of all diagnoses, our results reveal that 65% of our sample have more than a dual diagnosis and that this is more frequent in persons with severe and profound intellectual disability (84.7%) compared to persons with mild intellectual disability (54.8%).

**Conclusions:** The total prevalence of all psychiatric disorders decreases with severity of intellectual disability. These data are consistent with other studies, which found a lower prevalence of psychiatric disorders in participants with severe and profound intellectual disability. Our results also reveal that the total prevalence of all diagnoses increases with severity of intellectual disability, which is consistent with the literature since some authors underline the presence of multiple pathologies associated with intellectual disability. In general, our results are encouraging and suggest a progress in defining more precise diagnostic methods.

**Keywords:** *intellectual disability (ID); pervasive developmental disorders (PDD); dual diagnosis*

## Introduction

Persons who have both an intellectual disability and a mental disorder diagnosis are gaining more attention in the mental health context and the difficulty of diagnosing mental illness, particularly in persons with intellectual disability, is well known. For a long time psychiatric symptoms were associated with and considered as secondary to the cognitive limitations [1]. For example, on the

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one hand, many behavioural problems were considered as a type of aetiologic characteristic of intellectual disability. On the other hand, some authors suggested that a low IQ excludes the presence of psychiatric disorders [2], considering intellectual disability and psychiatric disorders as being mutually exclusive [3]. Other authors believed that persons with intellectual disability are protected from certain psychological stress and therefore are less prone to develop psychiatric illness [4]. Today, psychiatric disorders are considered as being linked to intellectual disability. This means they lead up to a diagnosis separate from intellectual disability and are no longer an integral part of this diagnosis. Furthermore, persons with intellectual disability are now considered as more vulnerable to psychosocial stress than persons without intellectual disability and therefore are more likely to develop mental disorders.

Originated around 1980, the concept of dual diagnosis is a conceptualisation of comorbidity which refers to coexisting intellectual disability and mental disorder [5–8]. Prior to this, the presence of intellectual disability reduced the diagnostic significance of behaviours that normally constitute psychiatric symptoms [9]. In 1985 Lund [10] reported the difficulty to reach a diagnosis for persons with intellectual disability and even more the adaptation of psychiatric diagnosis in a population with intellectual disability. The co-diagnosis of intellectual disability and psychiatric disorders is indeed not an easy one. The presence of psychiatric disorders may compromise the appreciation of IQ (or any other test) and reciprocally, cognitive deficit may mask the presence of psychiatric disorders [11].

Studies on the prevalence of psychiatric disorders in persons with intellectual disability have yielded inconsistent results. In her review of the literature Borthwick-Duffy [12] reported that the rate of psychiatric diagnoses in intellectual disability varies between 10% and more than 80%. Many issues make it difficult to obtain an accurate assessment of mental health in persons with intellectual disability. Signs and symptoms of psychiatric disorders in persons with intellectual disability may not correlate well with the diagnostic criteria within the DSM-IV-TR [13] or the ICD-10 [14]. Other factors which may compromise the value of classification criteria include for example impaired communication skills, impoverished social skills, stress-induced disruption of information processing, pre-existing cognitive deficits and maladaptive behaviours that distort symptoms and signs, and overshadowing. Besides the diagnostic criteria, assessment of the prevalence of dual

diagnosis may also vary according to the age and location of the population studied, definitions of intellectual disability and mental disorders, exclusion or inclusion of challenging behaviour, and the instruments used [15].

Furthermore, several risk factors threaten the person with intellectual disability, such as genetic abnormalities, brain injuries, adverse effects of treatment, vulnerability to abuses, stigmatisation and social exclusion, restrictions on possible activities, a certain lack of self-esteem and general difficulties with integration into society [16]. In addition, the presence of a somatic multi-pathology is extremely frequent in populations with intellectual disability and requires a close collaboration with somatic MDs: general practitioners, house physicians, neurologists, orthopaedists, endocrinologists, radiologists, oto-rhino-laryngologists and dentists [17–21].

Despite the numerous studies on the prevalence of psychiatric disorders in persons with intellectual disability, very few analyse this prevalence considering the different intellectual disability levels, or they only consider some of them [4]. Persons with intellectual disability form a very diverse group, from those with mild disability to persons who have profound disability. The ABC for Mental Health [22] gives the distribution of those different degrees of intellectual disability: mild intellectual disability making up 80% of the recorded population, moderate 12%, severe cases 7% and profound cases 1%. Even though a large majority of mild intellectual disability does not need any health care, some of them need specific support like psychiatric care. We may legitimately think that the rest of the population with intellectual disability (moderate, severe and profound) would also greatly benefit from it.

With respect to somatic disorders, several studies underline the need of care [18–20]. Obviously, the more detailed information the patient provides, the better his/her problems can be understood, allowing a correct diagnosis and suitable care. This logical sequence is not always completely possible with persons with intellectual disability, because of their limited verbal skills and comprehension. The interaction between various psychiatric and somatic diseases makes the care process even more difficult and delicate.

The right to receive care starts with the right to receive the most precise and complete diagnosis, thus ensuring access to adequate and adapted therapy. Consequently, it appears essential to have objective data concerning psychiatric and somatic diagnoses in the population with intellectual disability, in order to adapt the interventions to the

patient's specific needs and to refine the diagnostic tools. In the Canton of Geneva the diagnostic tool for psychiatric disorders is the International Statistical Classification of Diseases and Related Health Problems (ICD-10) [14].

Belonging to the Psychiatric Department of the University Hospitals of Geneva (HUG), the Psychiatric Unit of Mental Development (UPDM) works in coordination with the intellectual disability network of the Canton of Geneva in Switzerland. UPDM welcomes patients with mental retardation and associated psychiatric disorders. A pluridisciplinary team includes physicians, psychologists, nurses, speech therapists, physiotherapists, educators and social assistants. UPDM includes an ambulatory section (day hospital, mobile team and consultation) and two psychiatric hospital units. Those different structures of the UPDM were created to address specific therapeutic needs, to obtain environmental observations of persons with intellectual disability while they engage in their daily activities [11, 23, 24] and to cover the needs of families and socio-educational teams in the partnership of care.

Dedicated to persons facing acute situations whose condition does not need a full hospitalisation but whose consultation care plan is insufficient, the day hospital is focused on avoiding and shortening hospitalisation. The mobile team provides crisis and structured support interventions and direct counselling with a therapeutic presence on the field for patients, their family and the caregiver of the socio-educational institutions. Finally, the consultation is mainly directed to persons living with their family (sometimes in their own residences) or in different institutions with the objective of guaranteeing care continuity.

The two hospital units receive the patients during their hospitalisation, in the crisis unit or the rehabilitation unit (for short and middle-term stays). In addition to medical treatment, the hospital provides first assessments (psychological, social and psychomotor) in order to install an appropriate personalised programme. The hospital units have 18 + 1 beds.

Since the population with intellectual disability is characterised by a very wide spectrum of intellectual disability levels and psychiatric troubles [25] and since studies on the prevalence of psychiatric disorders in persons with intellectual disability have not yielded univocal results, we need objective data concerning the population monitored by the UPDM. The aim of the present study is then to investigate the association between severity of intellectual disability and prevalence of psychiatric disorders and somatic problems in a

population of adults who are treated in the Psychiatric Unit of Mental Development in Geneva, Switzerland.

## Method

### Data source

The present study is based on the analysis of the medical record of all ambulatory patients of the UPDM treated in March 2008. This population presents at least a dual diagnosis of intellectual disability associated with psychiatric disorders [23] based on the International Statistical Classification of Diseases and Related Health Problems criteria (ICD-10) accepted by the World Health Organisation. Concerning intellectual disability, the diagnosis is principally based on Wais-R/III, and for pervasive developmental disorders the diagnosis is principally based on AAPEP and CARS. All those evaluations are performed by psychologists and psychiatrists of the UPDM.

The data are recorded in administrative files and completely anonymous with the use of a code for each patient [11].

### Statistical analysis

Contingency tables were analysed with the Fisher's exact test. Statistical analyses were performed with the SPSS package, version 11 (SPSS Inc., Chicago, IL). Significance level was set at  $p < 0.05$  (two-sided tests).

## Results

The population with intellectual disability using our ambulatory service totals 302 patients, aged 16 to 70 (mean = 37.0; SD = 13.2). The distribution of intellectual disability levels results in the following spread. Our population of 302 participants shows a prevalence of *mild* (41.7%) and *moderate* (29.5%), followed by *severe* (11.3%), *profound* (8.3%) and *unspecified* intellectual disability level (4.0%). The remaining 5.3% of the sample, that is 16 participants, show an IQ superior to 70 (see table 1). Of the 302 participants 182 (60.3%) are men and 120 (39.7%) are women. The Fisher's exact test reveals no significant difference, meaning that this gender distribution is the same in each intellectual disability level (see table 1).

Since the present study aims to study psychiatric and somatic comorbidity according to the severity

of intellectual disability, the 16 participants who do not present an intellectual disability and the 12 participants who have an unspecified intellectual disability are excluded from the following analyses, which are then computed on a total sample of 274 participants. Since the distinction between severe and profound intellectual disability levels may be ambiguous, we considered them together as one intellectual disability level. This new sample shows a prevalence of *mild* (46.0%) and *moderate* (32.5%), followed by *severe-profound* (21.5%) intellectual disability levels (see table 2).

## Psychiatric diagnoses

Table 2 shows that 162 patients, who represent 59.1% of the total sample, have behavioural disorders. Statistical analysis reveals that behavioural disorders increase significantly in severe-profound intellectual disability level (79.7%) ( $p < 0.01$ ). In the mild intellectual disability level group there are significantly less patients who show behaviour disorders (47.6%) compared to those who do not show behaviour disorders ( $p < 0.01$ ). For behavioural disorder we consider the ICD-10 [14] definition which uses the code F7X.1 for a signifi-

**Table 1** Intellectual-disability-level distribution in men and women.

| gender         | intellectual disability level |                |           |                |           |                |           |                |             |                |           |                |            |                |
|----------------|-------------------------------|----------------|-----------|----------------|-----------|----------------|-----------|----------------|-------------|----------------|-----------|----------------|------------|----------------|
|                | mild                          |                | moderate  |                | severe    |                | profound  |                | unspecified |                | IQ >70    |                | total      |                |
|                | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n         | % <sup>a</sup> | n         | % <sup>a</sup> | n           | % <sup>a</sup> | n         | % <sup>a</sup> | n          | % <sup>b</sup> |
| men            | 76                            | 60.3           | 56        | 62.9           | 16        | 47.1           | 17        | 68.0           | 9           | 75.0           | 8         | 50.0           | 182        | 60.3           |
| women          | 50                            | 39.7           | 33        | 37.1           | 18        | 52.9           | 8         | 32.0           | 3           | 25.0           | 8         | 50.0           | 120        | 39.7           |
| <b>total</b>   | <b>126</b>                    |                | <b>89</b> |                | <b>34</b> |                | <b>25</b> |                | <b>12</b>   |                | <b>16</b> |                | <b>302</b> |                |
| % <sup>b</sup> | 41.7                          |                | 29.5      |                | 11.3      |                | 8.3       |                | 4.0         |                | 5.3       |                | 100.0      |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 302)

**Table 2** Behavioural disorders linked to intellectual disability.

| behavioural disorders | intellectual disability level |                |           |                |                 |                |            |                |
|-----------------------|-------------------------------|----------------|-----------|----------------|-----------------|----------------|------------|----------------|
|                       | mild                          |                | moderate  |                | severe-profound |                | total      |                |
|                       | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n          | % <sup>b</sup> |
| present               | 60                            | 47.6           | 55        | 61.8           | 47              | 79.7           | 162        | 59.1           |
| absent                | 66                            | 52.4           | 34        | 38.2           | 12              | 20.3           | 112        | 40.9           |
| <b>total</b>          | <b>126</b>                    |                | <b>89</b> |                | <b>59</b>       |                | <b>274</b> |                |
| % <sup>b</sup>        | 46.0                          |                | 32.5      |                | 21.5            |                | 100.0      |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 274)

**Table 3** Pervasive developmental disorders among intellectual disability levels.

| pervasive developmental disorders  | intellectual disability level |                |           |                |                 |                |           |                |
|--|-------------------------------|----------------|-----------|----------------|-----------------|----------------|-----------|----------------|
|  | mild                          |                | moderate  |                | severe-profound |                | total     |                |
|  | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n         | % <sup>b</sup> |
| autism childhood onset F(84.0)   | 5                             | 35.7           | 14        | 63.6           | 30              | 76.9           | 49        | 65.3           |
| atypical autism F(84.1)  | –                             |                | –         |                | 2               | 5.1            | 2         | 2.7            |
| overactive disorders associated with intellectual disability and stereotyped movements F(84.4) | –                             |                | 1         | 4.5            | –               |                | 1         | 1.3            |
| Asperger's syndrome F(84.5)  | 1                             | 7.1            | 1         | 4.5            | –               |                | 2         | 2.7            |
| pervasive developmental disorders, unspecified F(84.9)   | 8                             | 57.1           | 6         | 27.3           | 7               | 17.9           | 21        | 28.0           |
| <b>total</b>   | <b>14</b>                     |                | <b>22</b> |                | <b>39</b>       |                | <b>75</b> |                |
| % <sup>b</sup>   | 18.7                          |                | 29.3      |                | 52.0            |                | 100.0     |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 75)

cant impairment of behaviour requiring attention or treatment which is not a part of another disorder (for example autism) which has been recorded on Axis III.

The most frequent psychiatric diagnosis associated to intellectual disability, which concerns 27.4% of our sample, are pervasive developmental disorders. Among pervasive developmental disorders, *autism childhood onset* (65.3%) and *pervasive developmental disorders, unspecified* (28%) are the most frequent diagnosis. The statistical analyses computed on the presence versus the absence of pervasive developmental disorders in our total population reveal that pervasive developmental disorders are significantly more frequent in the severe-profound intellectual disability level (66.1%), while they are significantly less frequent in the mild intellectual disability level (11.1%) ( $p < 0.01$ ) (see table 3).

Table 4 shows that patients present a large range of psychiatric comorbidities other than intellectual disability, pervasive developmental disorders and behavioural disorders. The most frequent psychiatric disorders are *mood disorders* (F30–39) (48 patients, 25.7%), *disorders of adult personality and behaviour* (F60–69) (35, 18.7%),

*neurotic, stress-related and somatoform disorders* (F40–49) (33, 17.6%) and *schizophrenia, schizotypal and delusional disorders* (F20–29) (32, 17.1%). We point out that every intellectual disability patient may have more than one psychiatric diagnosis. The psychiatric comorbidities also differ in nature depending on the intellectual disability level. Patients with mild intellectual disability level seem to be characterised by *disorders of adult personality and behaviour* (F60–69) (23.0%), *mood disorders* (F30–39) (22.1%) and *schizophrenia, schizotypal and delusional disorders* (F20–29) (20.4%). Persons with moderate intellectual disability levels are more susceptible to have psychiatric comorbidities like *mood disorders* (F30–39) (28.6%), *schizophrenia, schizotypal and delusional disorders* (F20–29) (16.1%), *neurotic, stress-related and somatoform disorders* (F40–49) (16.1%) and *disorders of adult personality and behaviour* (F60–69) (16.1%). Principally, persons with severe-profound intellectual disability level present *mood disorders* (F30–39) (38.9%) as well as *neurotic, stress-related and somatoform disorders* (F40–49) (33.3%).

Since the total prevalence of some psychiatric diagnoses is very low, we computed a Fisher's

**Table 4** Associated psychiatric diagnoses among intellectual disability levels.

| mental and behavioural disorders   | intellectual disability level |                |           |                |                 |                |            |                |
|--|-------------------------------|----------------|-----------|----------------|-----------------|----------------|------------|----------------|
|  | mild                          |                | moderate  |                | severe-profound |                | total      |                |
|  | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n          | % <sup>b</sup> |
| organic, including symptomatic, mental disorders (F00–09)  | 7                             | 6.2            | 5         | 8.9            | 2               | 11.1           | 14         | 7.5            |
| mental and behavioural disorders due to psychoactive substance use (F10–19)                            | 8                             | 7.1            | 3         | 5.4            | –               | –              | 11         | 5.9            |
| schizophrenia, schizotypal and delusional disorders (F20–29)   | 23                            | 20.4           | 9         | 16.1           | –               | –              | 32         | 17.1           |
| mood (affective) disorders (F30–39)  | 25                            | 22.1           | 16        | 28.6           | 7               | 38.9           | 48         | 25.7           |
| neurotic, stress-related and somatoform disorders (F40–49)   | 18                            | 15.9           | 9         | 16.1           | 6               | 33.3           | 33         | 17.6           |
| behavioural syndromes associated with physiological disturbances and physical factors (F50–59)         | 2                             | 1.8            | –         | –              | 1               | 5.6            | 3          | 1.6            |
| disorders of adult personality and behaviour (F60–69)  | 26                            | 23.0           | 9         | 16.1           | –               | –              | 35         | 18.7           |
| disorders of psychological development (F8X) <b>without pervasive developmental disorders</b> (F84)    | 3                             | 2.7            | 3         | 5.4            | –               | –              | 6          | 3.2            |
| behavioural and emotional disorders with onset usually occurring in childhood and adolescence (F90–98) | 1                             | 0.9            | 2         | 3.6            | 2               | 11.1           | 5          | 2.7            |
| <b>total</b>   | <b>113</b>                    |                | <b>56</b> |                | <b>18</b>       |                | <b>187</b> |                |
| % <sup>b</sup>   | 60.4                          |                | 29.9      |                | 9.6             |                | 100.0      |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 187)

Every intellectual disability patient may have more than one diagnosis.



exact test for each of them separately, considering the presence or the absence of the disorder in each intellectual disability level for the total population. The results show that *schizophrenia, schizotypal and delusional disorders* (F20–29) are present in

11.7% and *disorders of adult personality and behaviour* (F60–69) are present in 12.8% of the total population. Statistical analyses reveal that *schizophrenia, schizotypal and delusional disorders* (F20–29) and *disorders of adult personality and*

**Table 5** Number of psychiatric diagnoses in intellectual disability levels.

| total of psychiatric (F) diagnosis | intellectual disability level |                |           |                |                 |                |            |                |
|------------------------------------|-------------------------------|----------------|-----------|----------------|-----------------|----------------|------------|----------------|
|                                    | mild                          |                | moderate  |                | severe-profound |                | total      |                |
|                                    | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n          | % <sup>b</sup> |
| 0 diagnosis                        | 51                            | 40.5           | 49        | 55.1           | 42              | 71.2           | 142        | 51.8           |
| 1 diagnosis                        | 40                            | 31.7           | 27        | 30.3           | 16              | 27.1           | 83         | 30.3           |
| 2 or more diagnoses                | 35                            | 27.8           | 13        | 14.6           | 1               | 1.7            | 49         | 17.9           |
| <b>total</b>                       | <b>126</b>                    |                | <b>89</b> |                | <b>59</b>       |                | <b>274</b> |                |
| % <sup>b</sup>                     |                               | 46.0           |           | 32.5           |                 | 21.5           |            | 100.0          |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 274)

**Table 6** Nature of somatic disorders among intellectual disability levels.

| somatic disorders   | intellectual disability level |                |           |                |                 |                |            |                |
|---|-------------------------------|----------------|-----------|----------------|-----------------|----------------|------------|----------------|
|   | mild                          |                | moderate  |                | severe-profound |                | total      |                |
|   | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n          | % <sup>b</sup> |
| certain infections and parasitic diseases (A–B)   | 1                             | 5.0            | –         | –              | –               | –              | 1          | 0.9            |
| malignant neoplasms (C–D48)   | –                             | –              | 1         | 2.0            | 1               | 2.2            | 2          | 1.7            |
| neoplasm/diseases of the blood and the blood-forming organs and certain disorders involving the immune mechanism (D50–89) | 2                             | 10.0           | 2         | 3.9            | –               | –              | 4          | 3.4            |
| endocrine, nutritional and metabolic diseases (E)   | 1                             | 5.0            | 2         | 3.9            | 1               | 2.2            | 4          | 3.4            |
| diseases of the nervous system (G)  | 6                             | 30.0           | 20        | 39.2           | 16              | 35.6           | 42         | 36.2           |
| <i>epilepsy (G40)*</i>  | 4                             |                | 14        |                | 13              |                | 31         |                |
| diseases of the eye and adnexa (H)  | 3                             | 15.0           | 2         | 3.9            | 3               | 6.7            | 8          | 6.9            |
| diseases of the circulatory system (I)  | –                             | –              | 4         | 7.8            | 1               | 2.2            | 5          | 4.3            |
| diseases of the respiratory system (J)  | 1                             | 5.0            | –         | –              | –               | –              | 1          | 0.9            |
| diseases of the digestive system (K)  | –                             | –              | 2         | 3.9            | –               | –              | 2          | 1.7            |
| diseases of the musculoskeletal system and connective tissue (M)  | 1                             | 5.0            | –         | –              | 1               | 2.2            | 2          | 1.7            |
| diseases of genitourinary system (N)  | –                             | –              | 1         | 2.0            | 1               | 2.2            | 2          | 1.7            |
| certain conditions originating in the perinatal period (P)  | –                             | –              | 2         | 3.9            | 3               | 6.7            | 5          | 4.3            |
| congenital malformations, deformations and chromosomal abnormalities (Q)  | 4                             | 20.0           | 14        | 27.5           | 16              | 35.6           | 34         | 29.3           |
| symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R)                               | 1                             | 5.0            | 1         | 2.0            | –               | –              | 2          | 1.7            |
| injury, poisoning and certain other consequences of external causes (S–T)   | –                             | –              | –         | –              | 2               | 4.4            | 2          | 1.8            |
| <b>total</b>  | <b>20</b>                     |                | <b>51</b> |                | <b>45</b>       |                | <b>116</b> |                |
| % <sup>b</sup>  |                               | 17.2           |           | 44.0           |                 | 38.8           |            | 100.0          |

\* Epilepsy (G40) is not counted in the total.

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 116)

Every intellectual disability patient may have more than one diagnosis.

behaviour (F60–69) are significantly more frequent in the mild intellectual disability level (18.3% and 20.6% respectively) and significantly less frequent in the severe-profound intellectual disability level (0% in the two disorders) ( $p < 0.01$ ).

Table 5 shows that 83 patients (30.3% of the total sample) have one psychiatric diagnosis and 49 patients (17.9%) have two or more psychiatric diagnoses, while 142 (51.8%) have no psychiatric diagnosis. Statistical analyses reveal that there are significantly more participants with mild intellectual disability level who have two or more psychiatric diagnoses (27.8%), while there are significantly more participants with severe-profound intellectual disability level who do not have a psychiatric diagnosis (71.2%) ( $p < 0.01$ ).

## Somatic diagnoses

Psychiatric comorbidities may also be associated with somatic diseases. Table 6 illustrates the nature of the somatic disorders in detail. Of the total sample 85 participants (31.0%) show at least one or more associated somatic diagnoses (see table 8). These 85 participants present 116 diagnoses in total. Of these 116 diagnoses 42 (36.2%) are *nervous system diseases* (G), whereby most of the cases are represented by *epilepsy diseases* (G40). The statistical analyses computed on the presence versus absence of *nervous system diseases* reveal that these diseases are present in 15.3% of total population (274 patients) and are significantly less frequent in mild intellectual disability level (4.8%) ( $p < 0.01$ ).

**Table 7** Detail of the diagnosis class congenital malformations (Q00–89) and chromosomal abnormalities (Q90–99).

| congenital malformations, deformations and chromosomal abnormalities                   | intellectual disability level |                |           |                |                 |                |           |                |
|--|-------------------------------|----------------|-----------|----------------|-----------------|----------------|-----------|----------------|
|  | mild                          |                | moderate  |                | severe-profound |                | total     |                |
|  | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n         | % <sup>b</sup> |
| congenital malformations of the nervous system (Q00–07)                                | –                             |                | 1         | 7.1            | 2               | 11.8           | 3         | 8.8            |
| congenital malformations of eye, ear, face and neck (Q10–18)                           | –                             |                | 2         | 14.3           | 2               | 11.8           | 4         | 11.8           |
| congenital malformations of the circulatory system (Q20–28)                            | –                             |                | 1         | 7.1            | –               |                | 1         | 2.9            |
| other congenital malformations of the digestive system (Q38–45)                        | –                             |                | –         |                | 1               | 5.9            | 1         | 2.9            |
| congenital malformations and deformations of the musculoskeletal system (Q65–79)       | –                             |                | –         |                | 1               | 5.9            | 1         | 2.9            |
| other congenital malformations (Q80–89)  | –                             |                | 3         | 21.4           | 4               | 23.5           | 7         | 20.6           |
| Down's syndrome, unspecified (Q90.9)   | 1                             | 33.3           | 5         | 35.7           | 5               | 29.4           | 11        | 32.4           |
| other trisomies and partial trisomies of the autosomes, not elsewhere classified (Q92) | 1                             | 33.3           | –         |                | –               |                | 1         | 2.9            |
| deletion from autosomes, unspecified (Q93.9)   | –                             |                | 1         | 7.1            | –               |                | 1         | 2.9            |
| fragile X chromosome (Q99.2)   | 1                             | 33.3           | 1         | 7.1            | 2               | 11.8           | 4         | 11.8           |
| <b>total</b>   | <b>3</b>                      |                | <b>14</b> |                | <b>17</b>       |                | <b>34</b> |                |
| % <sup>b</sup>   | 8.8                           |                | 41.2      |                | 50.0            |                | 100.0     |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 34)

**Table 8** Number of somatic diagnoses in intellectual disability levels.

| total of somatic (A–Z) diagnoses | intellectual disability level |                |           |                |                 |                |            |                |
|----------------------------------|-------------------------------|----------------|-----------|----------------|-----------------|----------------|------------|----------------|
|                                  | mild                          |                | moderate  |                | severe-profound |                | total      |                |
|                                  | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n          | % <sup>b</sup> |
| 0 diagnosis                      | 113                           | 89.7           | 50        | 56.2           | 26              | 44.1           | 189        | 69.0           |
| 1 diagnosis                      | 7                             | 5.6            | 27        | 30.3           | 20              | 33.9           | 54         | 19.7           |
| 2 or more diagnoses              | 6                             | 4.8            | 12        | 13.5           | 13              | 22.0           | 31         | 11.3           |
| <b>total</b>                     | <b>126</b>                    |                | <b>89</b> |                | <b>59</b>       |                | <b>274</b> |                |
| % <sup>b</sup>                   | 46.0                          |                | 32.5      |                | 21.5            |                | 100.0      |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 274)

**Table 9** Number of all diagnoses in intellectual disability levels.

| total of all diagnoses (behaviour disorders, psychiatric and somatic) | intellectual disability level |                |           |                |                 |                |            |                |
|---|-------------------------------|----------------|-----------|----------------|-----------------|----------------|------------|----------------|
|   | mild                          |                | moderate  |                | severe-profound |                | total      |                |
|   | n                             | % <sup>a</sup> | n         | % <sup>a</sup> | n               | % <sup>a</sup> | n          | % <sup>b</sup> |
| 0 diagnosis   | 34                            | 27.0           | 7         | 7.9            | 2               | 3.4            | 43         | 15.7           |
| 1 diagnosis   | 23                            | 18.3           | 23        | 25.8           | 7               | 11.9           | 53         | 19.3           |
| 2 or more diagnoses   | 69                            | 54.8           | 59        | 66.3           | 50              | 84.7           | 178        | 65.0           |
| <b>total</b>  | <b>126</b>                    |                | <b>89</b> |                | <b>59</b>       |                | <b>274</b> |                |
| % <sup>b</sup>  | 46.0                          |                | 32.5      |                | 21.5            |                | 100.0      |                |

<sup>a</sup> % per intellectual disability level

<sup>b</sup> % of total sample (n = 274)

and significantly more frequent in moderate intellectual disability level (22.5%) ( $p < 0.05$ ) and severe-profound intellectual disability level (27.1%) ( $p < 0.01$ ).

There is also a high occurrence of *congenital malformations, deformations and chromosomal abnormalities* (Q) in our sample since 34 (29.3%) of the 116 diagnoses consist of at least one Q diagnosis (see table 6). Table 7 illustrates the nature of the *congenital malformations, deformations and chromosomal abnormalities* in detail. The most represented diagnosis is *Down's syndrome, unspecified* (32.4%). If we consider the prevalence of all *congenital malformations, deformations and chromosomal abnormalities* in our total population (12.4% of 274 patients), the analyses show that they are significantly more frequent in severe-profound intellectual disability level (27.1%) ( $p < 0.01$ ) and significantly less frequent in mild intellectual disability level (3.2%) ( $p < 0.01$ ).

Table 8 shows that 54 patients (19.7%) have one somatic disorder and 31 patients (11.3%) have two or more somatic disorders, while 189 patients (69.0%) have no somatic disorder. The analyses show that this proportion is different depending on the intellectual disability level. Indeed, there are significantly more patients with mild intellectual disability who do not have somatic disorders (89.7%), while there are significantly more patients with moderate intellectual disability who have one somatic disorder (30.3%). In the severe-profound intellectual disability level 55.9% have one or more somatic disorders ( $p < 0.01$ ).

#### Psychiatric and somatic diagnoses

If we add the intellectual disability diagnosis, the presence of behaviour disorders, the psychiatric and the somatic diagnoses, we obtain that 43 participants (15.7% of the total sample) have only an intellectual disability diagnosis, 53 (19.3%) have one diagnosis besides intellectual disability and

178 participants (65.0%) have two or more diagnoses besides intellectual disability (see table 9). The analyses reveal that there are more persons with mild intellectual disability who have only an intellectual disability diagnosis (27.0%), while persons with severe-profound intellectual disability have more than two diagnoses (84.7%) ( $p < 0.01$ ). Finally, there are more participants with a moderate intellectual disability level who have only one diagnosis besides intellectual disability (25.8%).

#### Discussion

The distribution of intellectual disability levels present in our population is different from the one found in the literature. The reason for this difference may be explained by the fact that our population represents only a little part of the whole intellectual disability population in Geneva. Since challenging behaviour increases with severity of intellectual disability [26], we may have an over-representation of moderate and severe-profound intellectual disability levels, which leads to a diminution of the mild intellectual disability level prevalence. Indeed, besides intellectual disability, around 60% of the UPDM population has behaviour disorders.

In our study, as far as sociodemographic data are concerned, intellectual disability is more common in men than in women (3:2 ratio), which mirrors the findings of other studies [12, 27, 28]. Furthermore, a majority of patients present behavioural disorders, which are usually the cause of hospitalisation in our psychiatric unit. The occurrence of challenging behaviours such as self-injury in the autistic population is very frequent and educational teams have the most substantial difficulties in managing those "noisy" disorders, which often lead them to exhaustion.

Problems regarding the manifestation of psychiatric disorders vary widely in our population. For example, pervasive developmental disorders



diagnosis is more frequent in severe-profound intellectual disability level, which mirrors other findings [29]. One third of the psychiatric disorders of our population are pervasive developmental disorders. This fact is coherent with Crews et al. [28] and Fombonne [30] who show a large prevalence for pervasive developmental disorders over other disorders of psychological development. Anecdotally, the majority of patients without intellectual disability (IQ >70) consult our specialised service because they are concerned by pervasive developmental disorders and disorders of psychological development.

Crews et al. [28] point out that the persons with intellectual disability may develop psychiatric disorders as any other person. Their results underline that diagnoses relating to psychosis, for example, diminish with increasing intellectual disability as well as mood, personality and anxious disorders which are more present in mild and moderate levels, while mental organic disorders are mostly present in severe intellectual disability populations. In our population psychiatric diagnoses of *schizophrenia, schizotypal and delusional disorders* (F20–29) as well as diagnoses of *adult personality disorders and behavioural disorders* (F60–69) are more frequent in persons with mild intellectual disability and absent in severe-profound intellectual disability. Despite the non-significant results, mood disorders were also more frequent in mild intellectual disability level. These results are consistent with previous studies, which underline that this kind of diagnoses needs indeed a relatively important skill in verbal communication. The lack of this kind of diagnosis is then possibly due to this reason and not to the absence of the disorder.

Considering the total prevalence of psychiatric diagnoses, our data are also consistent with those of other studies which found a lower prevalence of psychiatric disorders in participants with severe-profound intellectual disability compared with participants with mild or moderate intellectual disability [26, 31]. According to Holden and Gitlesen [31], who used the Mini PAS-ADD to diagnose psychiatric disorders, these results reflect problems in detecting symptoms in persons with severe-profound intellectual disability, rather than a difference in prevalence of mental illness. It is indeed still a matter of debate whether rates of psychiatric disorders in severe-profound intellectual disability level are really less frequent or clinicians fail to understand the psychopathology in these patients because of their poor language and cognitive skills [31]. Nevertheless, Holden and Gitlesen [31] underline that some diagnoses like challenging behaviour increase with severity of

intellectual disability and that the prevalence of other psychiatric disorders may then be higher than apparent in persons with severe or profound intellectual disability.

Even though these results might suggest that for nearly ten years the diagnosing process has improved, we have to put it into perspective. In fact, diagnoses such as pervasive developmental disorders unspecified, unspecified disorders of psychological development or unspecified intellectual disability are still overemployed. This suggests that diagnostic tools need to be more precise, mainly to detect the under-threshold cases, which remain “unspecified” or “overshadowed”. This improvement in the diagnostic process still reflects a social process by which society has become more aware of the presence and needs of persons with intellectual disability [32]. The population with intellectual disability today actually benefits from more adapted carefulness and social structures than in the past. The increasing interest and literature regarding the quality of life of persons with intellectual disability is an indication of this consciousness raising.

Persons with intellectual disability also seem to be more subject to somatic diseases. Thirty-one per cent of clients present one to six different somatic comorbidity diagnoses. The most frequent somatic diagnoses among this population are diseases of the nervous system, especially epilepsy, and congenital malformations, deformations and chromosomal abnormalities. This may explain a “domino cascade effect” of somatic problems. Half of the latter class concern chromosomal abnormalities, such as Down’s syndrome unspecified, other trisomies and fragile X chromosome which are known to be a cause of intellectual disability. Down’s syndrome unspecified is the most present chromosomal abnormality in our population. Among congenital malformations (*in other congenital malformations*) one patient has a Prader-Willi syndrome, a congenital malformation syndrome predominantly associated with short stature. This diagnosis is an example of the importance of extensively exploring all the concomitant elements of intellectual disability: the more detailed the diagnoses of persons with intellectual disability are, the more detailed and adapted the care plan will be. This detailed list of different chromosomal abnormalities may be precious to stimulate research and, more importantly, it could become a clinical instrument of care.

Furthermore, our results reveal that diseases of the nervous system are significantly more frequent in the severe-profound intellectual disability level and significantly less frequent in the mild intel-

lectual disability level. These data are consistent with the literature, since epilepsy has shown a significant association with low levels of understanding [33]. Our results also reveal that congenital malformations, deformations and chromosomal abnormalities are significantly more frequent in severe-profound intellectual disability level, while they are significantly less frequent in mild intellectual disability level. This particular result is ambiguous since it is difficult to establish a correlation between the chromosomal abnormalities and the intellectual disability level. Indeed, we know the extreme variability of IQ evaluation between persons who have the same chromosomal abnormality as trisomy 21 for example.

Considering the total prevalence of somatic diagnoses, our data reveal that a majority of persons with severe-profound intellectual disability have at least one somatic disorder while only 10% of persons with mild intellectual disability have this type of diagnosis. The majority of the somatic disorders observed in our population consist in diseases of the nervous system and congenital malformations, deformations and chromosomal abnormalities. In most of the cases these disorders do not require an important skill in verbal communication in a person to be diagnosed and are then easier to diagnose than psychiatric disorders. Nevertheless, we cannot say if those results are consistent with the literature since there are no studies to which we could refer.

In our population 31% have at least one somatic diagnosis and 48.2% have at least one psychiatric diagnosis, but if we consider all the possible diagnoses besides intellectual disability, that are behaviour disorders, somatic and psychiatric diagnoses, 65% of our sample have more than a dual diagnosis. Furthermore, more persons with mild intellectual disability than predicted seem to have just an intellectual disability diagnosis, while persons with severe-profound intellectual disability have more than two diagnoses.

Thus, the use of the medical record which includes the diagnoses obtained through different evaluations seems to be a good way to get an accurate view of the patient with intellectual disability. Of course, the presence of these different components makes the diagnostic process more complex, but a careful consideration must be given to the mutual influence between somatic and psychiatric elements. Accurate psychiatric and somatic diagnosis is an essential step in the management of an individual's mental health needs. It guides the clinician as to which treatment/interventions/supports are likely to be appropriate for that adult and confers some infor-

mation about a likely prognosis. It is a "shorthand" description of an adult's presentation and needs.

Our study does not claim to be exhaustive. We are aware that it has some limitations, such as the size of the sample, the specificity of our population having more than a double diagnosis, their particular socioeconomic and geographical context as well as the benefit of particular psychiatric care. The use of the medical record instead of a precise rating scale is also arguable since not every participant has had the same evaluation, but our results show that this method seems to be a good one in order to get an accurate evaluation of persons with intellectual disability until we find a better way.

Finally, this study underlines the relationship between different psychiatric and somatic diagnoses at different levels of intellectual disability and suggests that we have to concentrate on the effective identification of symptoms resulting in a correct diagnostic decision. With these data we hope to encourage future studies in the field and to find more adapted assessments. The use of adapted rating scales will help to formulate a more precise diagnosis in psychiatric disorders which results in more specific and effective medical and therapeutic treatments. This will decrease the number of underdiagnoses which result in poor management and non-specific treatment plans.

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