Research Article



Injury Patterns among Individuals Diagnosed with Infantile Autism during Childhood: A Case-Control Study

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Abstract

Background: To date, injury risk among people with infantile autism (IA) has been a relatively poorly researched issue. **Objective:** The purpose of our study was to compare the prevalence and types of injuries in a clinical sample of 118 patients diagnosed with IA during childhood with those of 336 age- and sex-matched controls from the general population. **Method:** All participants were screened through the nationwide Danish National Hospital Register. The average amount of

time that the participants were observed was 30.3 years (range, 27.3 to 30.4 years), and the mean patient age at the end of the observation period was 42.7 years (range, 27.3 to 57.3 years).

Results: Among the 118 patients with IA, a total of 52 (44.1%) were registered in the Danish National Hospital Register with at least one injury diagnosis. In the comparison group, 226 of 336 individuals (67.3%) had at least one such diagnosis. The difference is statistically significant (P < .0001; odds ratio, 0.4; 95% confidence interval, 0.3 to 0.6), and the nature of the injuries also seems to differ. Gender, intellectual level, and concurrent epilepsy were not predictive of injury risk.

Conclusions: Our results lend support to the notion that injuries that require medical attention are not uncommon among an adult population of people diagnosed with IA during childhood, but they are less common than the rate found in a comparison group from the general population. It is proposed that a diagnosis of IA is related to the likelihood of institutional care, which may have a protective effect with respect to acute hospital use.

Keywords: infantile autism; injury; patterns of injury

Introduction

Infantile autism (IA) belongs to a group of neurodevelopmental disorders that are classified as pervasive developmental disorders or autism spectrum disorders (ASDs), of which IA forms the main prototype. IA is analogous to childhood autism as defined in the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) (1) and autistic disorder as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (2). The diagnosis is based on clinical criteria; people with IA have deficits in communication skills, impaired social interaction, and restricted interests. IA commonly co-occurs with intellectual disability (3), epilepsy (4), and attentiondeficit/hyperactivity disorder (5). Accumulating evidence indicates that people with these conditions

are at higher risk for injury or accidents than people without these conditions (6-8). In addition, the literature consistently reports higher rates of injury among males as compared with females (9).

To maintain the health and quality of life of people with ASD, it is important to minimize their risk of acquiring new disabilities. Understanding the risktaking behaviors and injury patterns of people with ASD can help to guide decision making related to long-term planning for individuals with ASD, and it can also have implications for health policy decisions. To date, the body of systematic research that addresses injury patterns in people with ASD is small. Two studies carried out in the United States have assessed the relationship between ASDs and injuries. In their study, Lee and colleagues (10) used parentreported injury data for the most recent 12 months

from 82 children with ASD between the ages of 3 and 5 years. The ASD diagnoses of the children were also parent-reported and not validated by clinicians. The studied children all participated in the National Survey of Children's Health. Results showed that participants with ASD were about two times more likely to experience accidents that required medical attention as compared with unaffected controls (24.2% vs. 11.9%). Males were 1.30 times more likely to have had an injury as compared with females. In another study, McDermott and colleagues (11) compared differences in the frequencies and types of injuries of 1610 children and adolescents with ASD between the ages of 1 and 18 years old and 91,571 typically developing peers. The authors used administrative data from Medicaid, which insured both study groups. The observation period was the 12 months of 2003. The results indicated that the risk of receiving emergency department or hospital treatment for any injury was elevated in individuals with ASD. Participants with ASD had higher rates of head, face, and neck injuries and lower rates of sprains and strains. The researchers found this to be in agreement with the behavioral profile of people with ASD: they are less likely to compete in organized sports or to participate in group play, both of which may precipitate sprains and strains.

In the same vein, research suggests that elopement behavior among children with ASD increases their risk of injury or death and places a major burden on families and care professionals. Anderson and colleagues (12) observed that 48% of children with ASD had attempted to elope from a safe environment; this rate was nearly four times higher than that of their unaffected siblings. In particular, participants with more significant ASD symptom severity were more likely to engage in risk-taking behaviors and to sustain frequent injuries. Of those who had run away, 24% were in danger of drowning and 65% were in danger of traffic injury, which suggests that addressing elopement behavior is an important intervention for many children with ASD. Cavalari and Romanczyk (13) reported that the likelihood of sustaining more frequent injuries increases with a child's engagement in more risktaking behaviors.

The purpose of the present study is to expand on the study of injury treatment among children and adolescents with ASD by Lee and colleagues (10) and McDermott and colleagues (11). We have the ability to study injury patterns in a sample that includes adults who were originally diagnosed with IA during childhood. On the basis of the outlined literature, we hypothesized that participants with diagnoses of IA would display higher rates of injury as compared with non-autistic community controls who were individually matched for gender, chronological age, place of birth, and social class. It was further hypothesized that male gender or a concurrent diagnosis of intellectual disability or epilepsy would be associated with an elevated risk for injury.

Participants and Methods

Case group

The case group was recruited from the population of patients consecutively attending the Departments of Child Psychiatry in the university hospitals of Copenhagen (the capital of Denmark) and Aarhus (the second largest city in Denmark) from 1960 through 1984 inclusive. They were selected at that time to participate in a study of parental age (14). The clinics provided services to the entire population of Denmark. All patients who were given a diagnosis of childhood psychosis-the ICD-8 term for ASDs, including borderline autistic condition-were rediagnosed by the first two authors in 1985 in accordance with the ICD-9 criteria (15). The core symptomatology of IA according to the ICD-9 is essentially similar to that later delineated for childhood autism in the ICD-10 (1). The revised diagnosis was based on a review of the patient's child psychiatric records. As a result of this rediagnosis, 118 individuals (85 males and 33 females) with IA were identified. These 118 patients make up the case group for the current study. At their index admission during childhood, the mean age of the case group was 4.9 years (median, 4.0 years; range, 2 to 15 years). All but one medical record included information about the intelligence quotient (IQ): 53 (45%) individuals had an IQ of less than 50; 30 (25%) had an IQ of between 50 and 69; and 34 (29%) had an IQ of more than 69.

Comparison group

A comparison group was retrieved from the Danish Civil Registration System. This register was established on April 2, 1968, and all persons alive and living in Denmark were enrolled at that time. Since then, all persons with permanent residence in Denmark have been added to this register, including every live-born baby and every new inhabitant (16). All persons in the register are assigned a unique identification number called a CPR number, which is then used in all national registers to enable accurate linkage among them. In the current study, wherever possible, each child with IA was matched with three control children by sex, time of birth (the controls were born the same day or the day before or after the patient), place of birth (region), and social group. In 6 cases, it was not possible to select three matched controls, because the patients in question were born abroad; this led to the loss of 18 controls. Consequently, the comparison group included 336 participants (246 males and 90 females).

Hospital register

All participants were screened through the Danish National Hospital Register (DNHR) (17) with the use of their CPR numbers. The register holds information about all individuals discharged from Danish medical hospitals since January 1, 1977; information about visits to outpatient clinics and emergency departments has been included in the register since January 1, 1995. In Denmark, all hospital and outpatient treatment is offered to all Danish citizens regardless of their socioeconomic status, because all treatment is paid for via the tax system. No matter where in the country diagnoses and treatments are given, all patient contacts are registered in the DNHR.

Members of both groups were followed from their birthdays or January 1, 1977 (whichever came later), until May 15, 2007 (the closing date of the observation period). The average observation period was 30.3 years (standard deviation [SD], 0.4 years; range, 27.3 to 30.4 years), and the mean age at the end of the observation period was 42.7 years (SD, 7.7 years; range, 27.3 to 57.3 years). The mean age at the start of the register-based observation period for injuries was 12.4 years. When calculating the mean age at the end of the observation period, we assumed that an individual had been alive throughout the observation period.

For individuals registered in the DNHR, we ascertained the place of admission, the dates of admission and discharge, the primary diagnosis, and eventually one or more secondary diagnoses. The register provides diagnoses according to the ICD-8 (18) and, after January 1, 1994, the ICD-10 (1).

The conditions inquired about for the current study included injuries, poisoning, and certain other consequences of external causes and epilepsy. Claims with ICD-8 diagnoses codes 800.xx through 999.xx or ICD-10 diagnoses codes S00.x through T98.x were used to define these injuries.

We counted the total number of injury-related diagnoses for each participant. The total number of injury diagnoses during the observation period was used to classify each participant into one of three groups by the number of DNHR diagnoses: one diagnosis, two to four diagnoses, or five or more diagnoses. In addition, each type of bodily region was counted independently so that a count was given for a specific type (e.g., fracture) or location (e.g., ankle and foot) of injury if the ICD-8 or ICD-10 codes for that type or location of injury were registered during an episode of care. For example, a person who experienced both an arm and a foot injury on the same day would be counted in the outcome groups for both arm and foot injuries. Participants with epilepsy were identified with a diagnostic code related to epilepsy: ICD-8 codes 345.xx or ICD-10 codes G40.x and G41.x. To simplify data presentation, all diagnoses are listed as ICD-10 diagnoses.

Statistical Analysis

Data handling and statistical analysis were performed with the use of the STATISTIX PC software packages (19). Comparisons between groups were based on the two-sample *t*-test for continuously scaled data and Fisher's exact test for dichotomous (present, absent) data. A probability value of less than 0.01 per a two-tailed test was used to indicate significant differences between the groups.

Ethics

The Danish Data Inspectorate approved the study protocol.

Results

Prevalence of injury

Table 1 summarizes the prevalences and types of injuries in the case and comparison groups.

At the end of the observation period, a total of 52 people with IA (35 males and 17 females) were found in the DNHR to have diagnoses of any injury variants (ICD-10 codes S00 through T98). The corresponding figure from the comparison group was 226 (169 males and 57 females). The overall prevalence of any injury among patients with IA was 52 out of 118 (44.1%). This is statistically significantly lower than the injury prevalence found in the comparison group, which was 226 out of 336 (67.3%; P < .0001; odds ratio [OR], 0.4; 95%confidence interval [CI], 0.3 to 0.6). However, the nature of the injuries seen in these two groups were somewhat different. When males and females were analyzed separately, the difference was still highly significant for males (35 out of 85 [41.2%] vs. 169 out of 246 [68.7%]; P < .0001; OR, 0.3; 95% CI, 0.2 to 0.5) but not for females (17 out of 33 [51.2%] vs. 57 out of 90 (63.3%); *P* = .30; OR, 0.6; 95% CI, 0.3 to 1.4).

Number of injury diagnoses

A total of 250 injury diagnoses had been recorded in the DNHR among the 118 individuals with IA (mean, 2.1; SD, 5.1; range, 0 to 36). In the comparison group, there were 1101 diagnoses (mean, 3.3; SD, 5.3; range, 0 to 46; two-sample *t*-test, t = – 2.07; degrees of freedom = 452; P = .04 [equal variance]). In total, 66 of 118 individuals in the case group (55.9%) and 110 of 336 individuals in the comparison group (32.7%) had no injury diagnoses recorded in the DNHR during the observation period (P < .0001; OR, 2.7; 95% CI, 1.7 to 4.2). Fifteen of 118 individuals with IA (12.7%) as compared with 60 of 336 individuals in the comparison group (17.9%) had one injury diagnosis in the register (P = .25; OR, 0.7; 95% CI, 0.4 to 1.2). The corresponding numbers with respect to two to four injury diagnoses were 23 of 118 individuals (19.5%) and 76 of 336 individuals (22.6%), respectively (P = .51; OR, 0.8; 95% CI, 0.5 to 1.4). For five or more injury diagnoses, the numbers were 14 of 118 individuals (11.9%) and 90 of 336 individuals (26.8%), respectively (P = .0008; OR, 0.4; 95% CI, 02 to 0.7). Most participants in the study had a low number of injury diagnoses (i.e., one to four) in the DNHR. However, participants in the comparison group represented a statistically significant larger proportion of the individuals who had received five or more injury diagnoses.

TABLE 1. Frequencies and types of injuries (International Statistical Classification of Diseases and Related Health Problems, 10th Revision codes in parentheses) in a sample of 118 individuals diagnosed with infantile autism during childhood and 336 matched controls from the general population*

	Individuals With Infantile Autism (n = 118)	Controls (n = 336)	P Values
Any injury, poisoning, or certain other consequences of external causes (S00-T98) (%) ⁺	52 (44.1)	226 (67.3)	<0.0001
Injuries to the head (S00-S09)	25 (21.2)	74 (22.0)	0.90
Injuries to the neck (S10-S19)	4 (3.4)	15 (4.5)	0.79
Injuries to the thorax (S20-S29)	0 (0.0)	21 (6.2)	0.009
Injuries to the abdomen, lower back, lumbar spine, pelvis and external genitals (S30-S39)	0 (0.0)	13 (3.9)	0.05
Injuries to the shoulder and upper arm (S40-S49)	9 (7.6)	27 (8.0)	1.00
Injuries to the elbow and forearm (S50-S59)	8 (6.8)	27 (8.0)	0.70
Injuries to the wrist and hand (S60-S69)	21 (17.8)	111 (33.0)	0.002
Injuries to hip and thigh (S70-S79)	3 (2.5)	13 (3.9)	0.60
Injuries to the knee and lower leg (S80-S89)	9 (7.6)	71 (20.1)	0.001
Injuries to the ankle and foot (S90-S99)	11 (9.3)	64 (19.0)	0.02
Unspecified multiple injuries (T00-T07)	2 (1.7)	9 (2.7)	0.74
Injury of unspecified body region (T08-T14)	4 (3.4)	10 (3.0)	1.00
Effects of foreign body entering throughnatural orifice (T15- T19)	6 (5.1)	28 (8.3)	0.31
Burns and corrosions (T20-T32)	3 (2.5)	10 (3.0)	1.00
Poisoning by drugs, medicaments, and biological substances (T36-T50)	2 (1.7)	6 (1.8)	1.00
Toxic effects of substances chiefly nonmedical as to source (T51-T65)	5 (4.2)	13 (3.9)	1.00
Other and unspecified effects of external causes (T66-T78)	2 (1.7)	4 (1.2)	1.00
Certain early complications of trauma (T79)	0 (0.0)	1 (0.3)	1.00
Complications of surgical and medical care, not elsewhere classified (T80-T88)	1 (0.8)	16 (4.8)	0.09
Sequelae of injuries, of poisoning and of other consequences of external causes (T90-98)	0 (0.0)	17 (5.1)	0.02

*Different injury types may co-occur in the same individual

⁺The diagnostic categories shown are those where at least one case or control were represented

Types of injuries

The injury types listed in Table 1 are not mutually exclusive; some participants had been recorded as having more than one type of injury at the end of the observation period. Most injury types occurred with nearly the same prevalence in the two groups. However, participants with IA had statistically significantly lower rates for injuries to the thorax (P = .009), the wrist and hand (P = .002), and the knee and lower leg (P = .001). In addition, there was a trend with respect to a lower rate of injury of the ankle and foot (P = 0.02) among those with IA.

Injuries and intelligence

Stratification of the 117 cases with known IQ values (the IQ of one case was unknown) into two groups with IQs of 69 or less (n = 83) or of 70 or more (n = 34) demonstrated no statistically significant difference between the two groups with respect to risk of injury (40 of 83 [48.2%] vs. 12 of 34 [35.3%]; P = .23; OR, 1.7; 95% CI, 0.8 to 3.9). However, there was a tendency for those individuals with IQs of 69 or less to present with injuries more frequently than those participants with IQs of 70 or more.

Injuries and gender

Among the 85 males with IA, 35 (41.2%) had received an injury diagnosis. For the 33 females with IA, 17 (51.2%) had received such a diagnosis. The difference was not statistically significant (P = .41; OR, 0.7; 95% CI, 0.2 to 1.5).

In the comparison group, 169 males and 57 females had injury diagnoses (169 of 246 [68.7%] vs. 57 of 90 [63.3%]; P = .35; OR, 1.3; 95% CI, 0.8 to 2.1). Thus, gender was not a statistically significant risk factor with respect to injury diagnosis in either group.

Epilepsy and risk of injury

Of the 118 individuals with IA, 29 (24.6%) received at least one epilepsy diagnosis; 5 individuals in the comparison group (1.5%) received such a diagnosis. Fourteen of the 29 individuals with both IA and epilepsy (48.3%) were also found to have an injury diagnosis. In the complementary group of the 89 individuals with IA but with no known epilepsy, 38 (42.7%) also had an injury diagnosis (P = .67; OR, 1.3; 95% CI, 0.5 to 2.9).

In the comparison group, 4 of the 5 individuals with epilepsy diagnoses (80.0%) were also found to have no injury diagnoses in the DNHR. In the complementary group of 331 individuals with no epilepsy diagnoses, 221(66.8%) were found in the DNHR to have injury diagnoses (P = .67; OR, 2.0; 95% CI, 0.2 to 18.0). Thus, epilepsy did not reach statistical significance or increase odds as a risk factor in either the case group or the comparison group.

Discussion

To our knowledge, this is the first study to investigate injury patterns in a population of adults with IA. Our study expands on two previous studies (10,11) that observed that children and adolescents with ASD were two times more likely to have experienced accidents that required medical attention as compared with controls without ASD. Contrary to our hypothesis and the above-mentioned results, we observed that a diagnosis of IA was associated with a lower rate of injury as compared with the rate seen among people of similar age and gender without IA from the general population. Of our 118 patients with IA, 44.1% had DNHR records of a diagnosis of any injury; the corresponding rate in the comparison group was 67.3% (P < .0001). Furthermore, individuals with IA also had a lower mean number of injury diagnoses as recorded in the DNHR (2.1 vs. 3.3 diagnoses; P = .04) than those in the comparison group from the general population. Most participants in both groups were registered in the DNHR with a low number of injury diagnoses (i.e., one to four). However, participants in the comparison group represented a significantly larger proportion of the

individuals that had received five or more injury diagnoses (11.9% vs. 26.8%). Taken as a whole, injuries that required medical attention were not uncommon in an adult population of people who had been diagnosed with IA during childhood, but they were less common than the numbers seen in a comparison group from the general population. However, the nature of the injuries in these two groups were somewhat different. Injuries to the thorax, wrist and hand, knee and lower leg, and ankle and foot were statistically significantly lower among participants from the IA case group.

What can be the explanation for the unexpected low prevalence of injuries and the reduced risks of certain types of injuries among the case group of individuals with IA? The reasons are not straightforward. Variability in sampling, diagnostic criteria, and methodology make it difficult to compare the studies that have been published so far. It is of particular note that, in Denmark, hospital treatment is offered to all citizens regardless of their socioeconomic status, because treatment is paid for via the tax system. Financial factors are thus less likely to influence pathways to care in this study as compared with studies from many other nations. The Danish setting therefore offers a unique opportunity to address the issue of equality of treatment for people with and without mental disorders.

We studied 118 carefully diagnosed people with IA. The two previously published studies (10, 11) included individuals with ASD diagnoses ascertained from parent-reports or Medicaid records. We also studied a much older age group than did Lee and colleagues (10) or McDermott and colleagues (11), who only included participants who were 18 years old or younger. With this in mind, it is important to note that the risks people face change with age and life stage. In other words, the risks that a toddler faces are not the same as the risks that a grandmother faces (20).

In Denmark, there is a long tradition of treating people with IA. This treatment, which is also offered to people with other developmental disorders, is provided through the government social care system, without charge to the individual and without the availability of private treatment settings. From a previously published study, we have been informed that many of our participants with IA have been living in long-term care settings for autistic people for many years (21). However, the exact number of participants with IA who were living in institutional settings at the end of the observation period is not known, and the duration of their placement in such settings is also unclear. The institutional environment may have a protective effect. A contributory explanation could be that many of these people's health needs are dealt with within the institution or

that there at least may be a greater threshold required before acute hospital care is deemed necessary (22). Consequently, this could bias our observations about lower injury rates. There is research from Denmark that shows that patient contact with hospitals as either inpatients or outpatients due to injury, poisoning, and certain other consequences of external causes (ICD-10 codes S00 through T98) is different before and after the diagnosis of ASD. Atladottir and colleagues (23) observed that children with ASD had a significantly higher risk of having hospital contact before the time of the ASD diagnosis as compared with children of the same age without ASD, but they also had a significantly lower risk of hospital contact after the time of the ASD diagnosis. These results suggest that the diagnostic process and the implementation of therapeutic and educational interventions may result in safer environments for this population. Another explanation may be that people with IA are less inclined to travel around in society and therefore they are at lower risk for accidents and injuries. For example, people with IA and other disabilities are unlikely to drive and may be less involved in accidents related to work and sport, so they may be at reduced risk for certain types of injuries, as suggested by our study. In the 2003 US National Survey of Children's Health, children with ASD were found to be less likely to participate in sports or extracurricular activities than children with other developmental disabilities (24). In line with this, Mangerud and colleagues (25) observed that adolescents with ASD had low levels of physical activity, and, of all the assessed diagnostic groups (i.e., adolescents with mood disorders, anxiety disorders, eating disorders, hyperkinetic disorders, or other disorders), the lowest rate of participation in team sports. The significantly reduced prevalence of injuries related to the wrist and hand, the knee and lower leg, and the ankle and foot observed in our case group may give support to these observations. However, we have no data related to sports and other physical activities, so caution is advised in the interpretation of these data.

Risk factors for injury

To reduce injury-related disability, it is important to identify the factors that contribute to an individual's predisposition to it. IA is an example of a disorder that commonly co-occurs with other disorders, such as intellectual disability (3) and epilepsy (4). These comorbidities can potentially increase the risk of injury among people with ASD (7,8). However, it is uncertain whether an increased risk of injury—if it exists—is related to the IA itself or to the concurrent conditions. In our study, injury risk was elevated (OR, 1.7) among the patients with IA who also had an intellectual disability (IQ < 70), but the difference did not reach statistical significance (P = .23). Epilepsy occurs in approximately 25% of people with IA, although rates from 5% to 40% have been reported (4), and there is widespread use of anticonvulsant medications among those who are affected. Epilepsy may predispose patients to injury as a result of falls and other accidents. In addition, anticonvulsant treatment may interfere with bone metabolism, affect bone quality, and increase the risk of fracture (8). However, epilepsy was not a risk factor in our study in either the case or the comparison group. Nevertheless, sample sizes were small, which raises the possibility that small or moderate effect sizes may have been missed.

The literature consistently reports higher rates of injury among boys as compared with girls (9,10). Contrary to our hypothesis, the expected gender difference in the injury rates was only observed in the comparison group (OR, 1.3), and it was not statistically significant (P = .43). Among people in the IA case group, more females than males had received a diagnosis of injury (51.2% vs. 41.2%; P = .41). Although the numbers are small, this observation is of particular interest, because several mortality studies have reported that the risk of death is greater among females with ASD than males with ASD (26).

Methodological considerations

When considering the results of our study, the strengths and weaknesses of the data must be recognized. Our results are based on register data that cover an entire national population, but the participants were not assessed face-to-face by the authors. It is a major advantage of this study that data were registered in a setting of universal health care, which virtually eliminates the risk of recall and selection bias. In addition, the use of register data provides complete follow-up information about all cases, without the attrition that may limit personal follow-up studies. A number of limitations of this study should also be considered. Our study focused on more severe injuries, which would be captured through hospital treatment and emergency department visits. It may be argued that inpatient admissions and, since 1995, outpatient data (including emergency department) are relatively crude measures of the injuries that occurred among the member of the two study groups. Relatively minor injuries for which no hospital treatment was sought may have escaped our attention and consequently biased our findings toward lower prevalence values for cases as well as controls. It is also important to emphasize that our results mainly apply to injuries among preteens, teens, and young adults: the participants were an average of 12.4 years old when they entered the observation period. Lastly,

we acknowledge the important limitation of our data not including information about the patient's activity (e.g., sports participation) when the injury occurred or the location in which the accident took place.

The issues related to the identification of participants with epilepsy have been published elsewhere (27). The validity of the medical data is unknown. The DNHR collects data for administrative purposes and not for research; therefore, the quality of the data may differ among hospitals. However, a validation study had estimated the quality of the diagnostic codes and the accident codes to be about 85%, and this has been confirmed (28). In another study that evaluated the quality of epilepsy diagnoses, the results showed that the positive predictive value of an epilepsy diagnosis in the DNHR was 81% (29).

In sum, as a consequence of their core symptoms or their accompanying disorders (e.g., epilepsy, learning disability), it would seem that people with IA may be at increased risk for injury. Alternatively, many of these patients live in institutional environments, and their reluctance to interact with society at large may have a protective effect. Although a few studies have indicated that injury risk is increased among children and adolescents with ASDs, the results from the current study lend no support to the hypothesis that injury risk is elevated in a population mainly composed of adults diagnosed with IA during childhood. However, these results may only be applicable in Danish society, where there is a long tradition of treating people with IA in institutional settings.

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