

Comparison of unmet health care needs in children with intellectual disability, autism spectrum disorder and both disorders combined

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Abstract

Background The purpose of this study was to assess the unmet health care needs of children with intellectual disability (ID) compared with children with autism spectrum disorder (ASD) and whether access to health insurance coverage is a contributing factor. Children with ID may be masked in the health care system due to increased diagnosis and awareness of ASD. The needs, unmet needs and insurance coverage of children with ID alone, ASD alone, and co-occurring ID and ASD were assessed in this study.

Methods The 2016 to 2019 United States' Census Bureau National Survey of Children's Health was used to determine differences in unmet needs, care not received and health insurance coverage during the past year for children with ID and/or ASD. Adjusted odds ratios and 95% confidence intervals for care not received were determined controlling for sex, insurance, race, age and parents' highest education level.

Results Children with ID were nearly four times more likely not to receive needed medical care as children with ASD. Results were similar for unmet hearing and mental health care. Children with both ID and ASD were more likely to have unmet health care but less likely to have unmet medical care

compared with children with ASD alone. There were no significant differences for unmet dental or vision care. Children with ID were 3.58 (95% confidence interval: 1.6–8.0) times more likely to have inconsistent health insurance compared with children with ASD.

Conclusions Children with ID alone are more likely to have unmet medical, hearing and mental health care needs than children with ASD alone. Children with co-occurring ID and ASD have a large amount of general unmet health care needs but less unmet medical needs. Children with ID are less likely to have consistent health insurance than children with ASD. This hinders the ability of children with ID to receive quality care. Further research is needed to determine if the diagnosis of ASD in children in the United States is negatively affecting children with ID alone.

Keywords autism spectrum disorder, intellectual disability, National Survey of Children's Health, special health care needs, unmet health care needs

Background

With the increase in awareness and diagnosis of autism spectrum disorder (ASD), concerns arise as to whether children with other disabilities are receiving the same health services and quality care as children with ASD in the United States (Baio *et al.* 2018, p. 9).

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Do children with intellectual disability (ID) have more unmet health care needs than children with ASD?

Do children with co-occurring ID and ASD have more unmet health care needs than children with ASD?

Do children with ID have consistent insurance that allows them to access the care they need?

Autism spectrum disorder and ID are common developmental disabilities. ASD is diagnosed when a child has social communication and interaction deficits, restricted and repetitive behaviours. ID is diagnosed when a child is noted to have impaired general mental abilities and impaired adaptive functioning throughout development (American Psychiatric Association 2013, pp. 33, 50–51). Recent studies report that 31% of children with ASD also meet criteria for ID (Baio *et al.* 2018, p. 9). Other impairments also occur at a higher rate in children with ASD and ID and require periodic assessments of hearing (Salt & Sargent 2014, p. 1167), vision (Ikeda *et al.* 2013, pp. 1449–1451; Nielsen *et al.* 2007, p. 424) and dental needs (Norwood *et al.* 2013, p. 618).

Unmet health care needs include inability to access necessary services, such as therapies, medicine, respite care or mental health care (Lindly *et al.* 2016, p. 713). No formal studies have been published regarding the unmet needs of children with a sole diagnosis of ID. Because individuals with ID are more likely to have co-existing physical disabilities, hearing problems, vision impairments, mental health issues and communication disorders (Ouellette-Kuntz *et al.* 2005, p. S9), ongoing surveillance and interprofessional care are recommended (Marrus & Hall 2017, p. 546).

Data from the 2016 National Survey of Children's Health (NSCH) showed that children with ASD can have four times as many unmet health care needs as children without ASD (Karpur *et al.* 2019, p. 1657). Previous studies reveal parents of children with ASD report inadequate insurance and lack of coordinated care (Vohra *et al.* 2014, p. 823), inability to get referrals (Kogan *et al.* 2018, p. 8) and unmet needs more than parents of children with other developmental disabilities (Curran *et al.* 2001, p. 532).

Children with both ID and ASD experience more cognitive, communication and behavioural impairments than ASD alone, which can make

providing care more difficult for health care providers (Menezes *et al.* 2021, p. 2200). Paediatric providers have expressed a lack of confidence in managing certain behaviours exhibited by children with ID (Ong *et al.* 2017, p. 299), which can be increased in children with co-occurring ID and ASD and can contribute to increased unmet health care needs compared with the general population (Menezes *et al.* 2021, p. 2200).

Insurance access, adequacy and consistency play a role in meeting a child's health care needs. In the United States, individual state health policies regarding insurance coverage influence access to care for children with special health care needs (CSHCN) (Sannicandro *et al.* 2017, p. 529; Tonnsen *et al.* 2016, p. 494). In the 2009–2010 NSCH, parents of children with ASD increasingly reported inadequate insurance coverage compared with parents of children with ID (Zablotsky *et al.* 2014, p. 399). However, as of 2019, every state has passed legislation requiring insurance coverage for ASD while similar legislation for ID is extremely variable (Barth *et al.* 2020, p. 11; National Conference of State Legislatures 2021).

In the United States, children can be insured through private insurance from their parents' workplace or a national marketplace, public insurance, a combination of the two, or completely lack health insurance. Care for CSHCN is more expensive than for children with typical needs, with most costs going toward special education services and parental productivity loss. The co-occurrence of ID with ASD in children increased the aggregated national cost of supporting these children in both the United States and the United Kingdom (Buescher *et al.* 2014, p. 726).

The purpose of this study was to assess the unmet health care needs of children with ID compared with children with ASD and children with ID and ASD and determine if there is an association with inconsistent or inadequate health insurance. No formal studies have been published regarding the unmet needs of children with a sole diagnosis of ID. We hypothesised that children with a diagnosis of ID have more unmet health care needs and inconsistent and inadequate insurance compared with children with a diagnosis of ASD with or without ID. This study will provide paediatricians and parents with information regarding whether CSHCN are receiving the care they require and whether there is a difference

between care received by children with ID or both ID and ASD versus children with ASD alone.

Methodology

Data and participants

The NSCH was conducted by the US Census Bureau annually between 2016 and 2019 (CAHMI 2019). A total of 131 774 families participated by providing information on a child in their home. Families were contacted with a pre-survey screener mailed to their home and asked about their four youngest children. One child was randomly chosen for the full survey. On a secure website, parents or caregivers (hereafter 'parents') answered questions about the child. Details about the survey methodology are available from the Health Resources and Services Administration website at <https://mchb.hrsa.gov/data/national-surveys/data-user>.

Measures

Twenty-six items related to disabilities, special health care needs and services utilised, and unmet health care needs were evaluated. Demographic data included child's age, sex, race, health insurance type, poverty level and highest level of education for the parent(s). Descriptive statistics are included in Table 1. A full list of questions used to create outcome measures is included in Table 2.

Data analysis

The NSCH identified children with diagnoses of ID and ASD based on parent report. Missing responses were excluded from analyses. Comparisons between children with ID, ASD, and both ID and ASD on demographics and the 19 outcome measures were made with χ^2 tests for categorical variables and one-way analysis of variance for continuous variables. When overall three-group comparisons were statistically significant, Bonferroni multiple *post hoc* comparisons were used to determine specific paired group differences. Multiple logistic regression was then used to determine adjusted odds ratios and 95% confidence intervals for all outcomes with significant univariate test results ($P < 0.05$). Adjusted odds ratios were adjusted for child's sex, health insurance, race, age and adult's education. All

analyses were performed with SPSS v28.0 Complex Samples Module (IBM Corporation, Armonk, NY) with weighting to consider the complex sampling design.

Results

Characteristics of the study participants

Seven hundred and sixty (0.6%) sample children in the NSCH were identified with ID, 2973 (2.6%) with ASD, and 577 (0.4%) with both ID and ASD. Table 1 shows the characteristics of the study participants and comparisons between the three groups on demographic variables. The mean (standard error) age of children with ID was 10.9 (0.3), children with ASD was 10.3 (0.2), and children with both ID and ASD was 11.1 (0.4), $P = 0.138$ (analysis of variance). A significantly higher percent of the children with ASD and children with both ID and ASD were males compared with children with ID. Children with ID or ID and ASD were more likely to have public or combined public and private insurance than children with ASD. There was no significant difference in the groups regarding race, adult's level of education, family poverty level, family structure or number of children in household. Most children with ID and/or ASD came from families with two married parents. Study participants were most likely to come from a household with one other child.

Special health care needs of children with intellectual disability and children with autism spectrum disorder

The NSCH used the CSHCN screener to assess qualification for services (Bethell *et al.* 2002, pp. 44–46). Many CSHCN receive services such as speech, occupational or behavioural therapy to meet their developmental needs. When comparing the children with both ID and ASD to the children with only ID or only ASD, significant differences were found in terms of meeting criteria for elevated use of services, functional limitations, specialised therapy, qualifying for needing treatment or counselling, and qualifying on mental health criteria (Table 2). No significant difference was found for meeting the criteria for prescription medications. Both children with ID alone and children with both ID and ASD

Table 1 Descriptive statistics and comparisons between children with ID, children with ASD and children with both ID and ASD

Variable	Children with ID, <i>n</i> (%)	Children with ASD, <i>n</i> (%)	Children with ID and ASD, <i>n</i> (%)	<i>P</i> value
Child's sex				<0.001
Male	417 (58.3)*	2387 (80.0)	446 (76.8)**	
Female	343 (41.7)	586 (20.0)	131 (23.2)	
Child's race				0.074
White	562 (57.6)	2288 (63.0)	435 (66.8)	
Black	85 (22.8)	214 (15.0)	56 (19.1)	
Other	113 (19.6)	471 (22.1)	86 (14.1)	
Insurance type				<0.001
Public	313 (51.5)*	879 (40.4)	220 (52.7)*	
Private	228 (22.7)	1660 (43.7)	177 (26.3)	
Public and private	179 (20.2)	309 (11.7)	150 (18.3)	
Uninsured	50 (5.6)	87 (4.2)	18 (2.8)	
Adults education				0.162
≤High school	187 (43.7)	479 (31.7)	104 (35.7)	
Some college	190 (22.3)	819 (26.7)	162 (24.9)	
≥Bachelor's degree	377 (34.0)	1656 (41.6)	306 (39.4)	
Family poverty level				0.384
0–99%	134 (28.4)	393 (22.4)	117 (31.3)	
100–199%	164 (27.8)	613 (30.1)	123 (24.3)	
200–399%	259 (25.9)	990 (26.6)	177 (26.9)	
≥400%	203 (17.9)	977 (21.0)	160 (17.5)	
Family structure				0.429
Two parents, currently married	271 (51.0)	1210 (59.2)	217 (55.0)	
Two parents, not currently married	26 (8.8)	139 (11.3)	22 (10.2)	
Single parent (mother or father)	122 (32.1)	431 (22.4)	101 (27.0)	
Grandparent household	29 (4.4)	96 (5.5)	15 (4.9)	
Other family type	21 (3.7)	19 (1.6)	8 (2.9)	
Number of children in household				0.350
1	304 (29.4)	1322 (29.4)	262 (27.5)	
2	275 (32.9)	1096 (37.0)	219 (45.5)	
3	132 (27.4)	417 (24.0)	67 (17.0)	
4+	49 (10.4)	138 (9.5)	29 (10.0)	

Values in the table are unweighted counts and weighted percents. Sample sizes may not total 760 for ID, 2973 for ASD and 577 for combined ID and ASD for individual variables due to missing data.

**P* < 0.05 vs. children with ASD.

***P* < 0.05 vs. children with ID, Bonferroni *post hoc* multiple comparisons.

had increased odds of meeting the criteria for functional limitations. Children with a combination of ID and ASD also had increased odds of meeting the criteria for elevated use of services. Children with ID had over double the odds of currently receiving special services to meet developmental needs compared with children with ASD. Children diagnosed with both ID and ASD had over twice the

odds of qualifying on mental health criteria compared with children with ASD.

Unmet needs

Parents who identified any general unmet health care needs over the past year were assessed regarding specific needs. Sixty-five children with ID (10.4%), 270 children with ASD (10.0%) and 87 children with

Table 2 Adjusted odds ratios (AOR)^a of having selected health care characteristics according to parent-reported intellectual disability (ID) and autism spectrum disorder (ASD) status, United States, 2016–2019

Outcome measures	Categories	Children with ID, n (%)	Children with ASD, n (%)	Children with ID and ASD, n (%)	Children with neither ID nor ASD, n (%)	Children with ID vs. children with ASD, AOR (95% CI)	Children with ID and ASD vs. ASD, AOR (95% CI)
Special health care needs of children with ID and children with ASD							
Child meets CSHCN screener for prescription medication criteria	Yes (vs. No)	447 (54.8)	1478 (47.0)	368 (53.4)	20 183 (12.4)	1.13 (0.8–1.6)	1.04 (0.7–2.6)
Child meets CSHCN screener for elevated use of services criteria	Yes (vs. No)	635 (75.5)	2226 (76.2)	545 (92.2)*, **	11 898 (7.7)	0.91 (0.6–1.5)	3.58 (1.8–7.0)
Child meets CSHCN screener for functional limitations criteria	Yes (vs. No)	594 (66.0)*	1560 (51.5)	530 (92.8)*, **	4341 (3.1)	1.72 (1.1–2.6)	13.90 (6.6–29.1)
Child meets CSHCN screener specialised therapy criteria	Yes (vs. No)	579 (66.7)	1757 (61.3)	521 (89.3)*, **	4,409 (3.3)	1.26 (0.8–1.9)	6.43 (3.6–11.4)
Child qualifies on the CSHCN screener ongoing emotional, developmental, or behavioural criteria for which treatment or counselling is needed	Yes (vs. No)	576 (71.0)	2156 (71.5)	528 (92.0)*, **	9,633 (6.3)	0.79 (0.51–1.23)	4.16 (2.31–7.51)
CSHCN with and without ongoing emotional, developmental and/or behavioural health special needs	Qualifying on MH criteria Not qualifying on MH criteria	576 (70.9) 138 (16.7)	2156 (71.3) 472 (15.8)	528 (92.0)*, ** 46 (7.6)	9633 (6.3) 16 457 (10.2)	0.77 (0.5–1.2) Reference	2.30 (1.3–4.2) Reference
Has this child ever received special services to meet his or her developmental needs such as speech, occupational or behavioural therapy? Is child currently receiving special services to meet developmental needs such as speech, occupational, or behavioural therapy?	Yes (vs. No)	689 (81.6)	2512 (83.5)	559 (93.6)**	17 644 (12.7)	1.14 (0.7–1.9)	3.42 (1.3–8.8)
During the past 12 months, did this child see a specialist other than a mental health professional?	Yes (vs. No)	607 (72.0)*	1724 (59.4)	481 (82.7)*	6742 (5.4)	2.31 (1.5–3.6)	4.22 (2.6–10.0)
How old was this child, in years, when he or she began receiving special services?	Yes, received care from a specialist No, but needed to see a specialist No, did not need to see a specialist At age less than 3 years old At age 3–5 years old At age 6–17 years old	410 (46.2)* 29 (4.9) 315 (48.9) 152 (25.8) 231 (45.1) 119 (29.1)	956 (30.4) 139 (5.7) 1856 (63.9) 584 (23.1) 1169 (52.7) 643 (24.2)	275 (39.6) 38 (8.8) 260 (51.5) 127 (22.8)** 280 (62.2) 77 (14.9)	20 377 (13.3) 1650 (1.6) 103 466 (85.0) 39 15 (25.3) 69 11 (42.0) 56 11 (32.7)	1.94 (1.3–2.8) 1.09 (0.5–2.3) Reference 1.64 (0.8–3.1) 0.97 (0.5–1.7) Reference	1.60 (1.0–2.5) 2.10 (1.0–4.5) Reference 2.77 (1.5–5.0) 2.33 (1.3–4.0) Reference

Table 2. (Continued)

Outcome measures	Categories	Children with ID, n (%)	Children with ASD, n (%)	Children with ID and ASD, n (%)	Children with neither ID nor ASD, n (%)	Children with ID vs. children with ASD, AOR (95% CI)	Children with ID and ASD vs. ASD, AOR (95% CI)
Unmet needs ^b							
During the past 12 months, was there any time when this child needed health care (of any type) but it was not received?	Yes (vs. No)	65 (10.4)	270 (10.0)	87 (16.2)	2816 (2.8)	1.08 (0.6–1.9)	1.79 (1.0–3.0)
During the past 12 months, was there any time when this child needed medical care but it was not received?	Yes (vs. No)	27 (50.6)*	49 (21.6)	12 (5.5)*, **	913 (35.2)	3.79 (1.3–11.4)	0.19 (0.1–0.6)
During the past 12 months, was there any time when this child needed dental care but it was not received?	Yes (vs. No)	39 (57.9)	85 (47.4)	27 (39.8)	1308 (53.8)	1.52 (0.5–4.4)	0.83 (0.4–2.0)
During the past 12 months, was there any time when this child needed vision care but it was not received?	Yes (vs. No)	14 (22.3)	39 (17.3)	14 (26.9)	494 (20.9)	0.65 (0.2–1.8)	1.29 (0.5–3.4)
During the past 12 months, was there any time when this child needed hearing care but it was not received?	Yes (vs. No)	12 (22.4)*	16 (3.8)	6 (3.1)**	136 (6.3)	7.31 (2.2–23.8)	0.56 (0.1–2.6)
During the past 12 months, was there any time when this child needed mental health services but it was not received?	Yes (vs. No)	25 (60.9)	145 (40.3)	47 (48.6)	865 (27.1)	2.77 (1.0–7.6)	1.43 (0.7–3.1)
Does this child's current insurance coverage meets his or her health needs?	Sometimes or Never	68 (9.5)	369 (11.8)	95 (18.5)	7552 (6.4)	0.99 (0.5–2.1)	2.12 (1.1–4.1)
	Usually	284 (40.8)	1076 (35.6)	219 (28.8)	34 383 (26.0)	1.48 (1.0–2.2)	0.92 (0.6–2.1)
	Always	373 (49.6)	1426 (52.6)	243 (52.7)	78 775 (67.6)	Reference	Reference
Does this child's current insurance coverage allows him or her to see needed provider?	Sometimes or Never	44 (9.0)	260 (7.9)	76 (15.5)	4155 (3.7)	1.62 (0.7–3.6)	2.90 (1.6–5.4)
	Usually	206 (30.1)	835 (25.6)	179 (24.1)	21 979 (17.4)	1.42 (0.9–2.1)	1.12 (0.7–1.7)
	Always	475 (60.9)	1772 (66.5)	303 (60.4)	94 461 (78.9)	Reference	Reference
Did this child have consistent health insurance coverage during the past 12 months?	Had a gap in coverage	57 (13.2)*	138 (6.0)	29 (4.9)**	6969 (8.6)	3.58 (1.6–8.0)	0.67 (0.2–1.8)
	Insured continuously all year	699 (86.8)	2818 (94.0)	543 (95.1)	118 430 (91.4)	Reference	Reference

AOR, adjusted odds ratio; CI, confidence interval; CSHCN, children with special health care needs screener.

Values in the table are unweighted counts and weighted percents. Weighted adjusted odds ratios are the odds for the ID group or the ID and ASD group, adjusted for child's sex, health insurance, race, age and adult's education. Children with neither ID nor ASD are excluded from all analyses.

*Reference category for all adjusted odds ratios is children with ASD only.

^bFor unmet needs, total sample size is $n = 65$ for ID, $n = 270$ for ASD and $n = 87$ for both ID and ASD.

* $P < 0.05$ vs. children with ASD.

** $P < 0.05$ vs. children with ID, Bonferroni *post hoc* multiple comparisons.

both diagnoses (16.2%) had unmet health care needs in general over the past year (Table 2). Children with both ID and ASD had 1.79 times the odds of having any type of unmet health care need compared with children with ASD. Children with ID had 3.79 times the odds of not receiving medical care that was needed compared with children with ASD, while children with both ID and ASD had 0.19 times the odds compared with children with ASD.

Additionally, children with ID had greater odds of not receiving needed hearing care compared with children with ASD only. Children with ID had nearly three times the odds of not receiving needed mental health care compared with children with ASD. No significant differences were found for dental or vision care.

There were significant differences among the three groups regarding having consistent insurance in the past year. In the univariate analyses, a significantly higher proportion of children with ID (13.2%) had a gap in coverage compared with the other two groups. There was no difference between children with ASD only (6.0%) and children with both ASD and ID (4.9%). Children with ID had over three times the odds of having a gap in insurance coverage compared with children with ASD in the past year. There was also a significant difference, but no variance in odds, of children with both diagnoses and children with ASD alone on whether the child's insurance coverage allows them to see their needed provider.

Frequencies for all the variables in children with neither ID nor ASD were assessed and are included in Table 2. However, the significance of these frequencies compared with the three groups studied was not assessed.

Discussion

This study assessed whether children with ID, with ASD and with ID and ASD have differences in their special health care needs, unmet health care needs and insurance access. There were multiple significant differences found in the needs of the three groups for the CSHCN screener. Children with ID have more functional limitations than their ASD counterparts, and receive more speech, occupational, or behavioural therapy and medical specialty care compared with children with ASD. When children have co-occurring ID and ASD, they also meet

criteria for increased service use, specialised therapy, mental health needs and substantial functional limitations.

This study suggests that children with ID alone have greater unmet medical, hearing and mental health care needs than children with ASD. In addition, children with co-occurring ID and ASD have greater unmet health care needs overall compared with children with ASD but have less unmet medical and hearing care needs compared with children with ASD. It is plausible that children with ID alone have more unmet medical needs than children with ASD due to having a larger number of health conditions, which result in more medical needs. This may indicate that similar medical needs are being addressed for both groups of children, but that the children with ID simply have more needs overall. However, it is remarkable that children with both diagnoses are less likely to have unmet medical and hearing care needs for this same reason. It could be possible that the diagnosis of ASD, whether alone or in combination with ID, is resulting in better access to services such as medical care and hearing care in the United States, allowing children with both diagnoses, but not ID alone, to be better connected for medical and hearing care. This could mean that children with ID truly are 'left behind' when it comes to advancements in care for children with developmental disabilities. More research investigating the difference between these groups and unmet health care needs is necessary. A significant number of children with ID have parents who feel there are unmet medical needs compared with their counterparts with ASD, which should be addressed to improve the care for these children. Children with delayed development in need of therapies have been shown to have increased parent-reported unmet health care needs (Magnusson *et al.* 2016, p. 151).

It is particularly interesting that there is a significant difference found between the groups of children regarding unmet needs for hearing care, although not for vision care. Children with ID, if associated with a genetic condition such as Down syndrome, have increased rates of vision and/or hearing deficits (Kinnear *et al.* 2018, p. 5). On the other hand, children with ASD tend to have preserved sensory function (Thurm *et al.* 2019, p. 5). Of course, other factors could come into play as well, such as premature births resulting in hearing loss (Van

Naarden Braun *et al.* 2015, p. 15). The non-significant differences in dental and vision care may be due to an overwhelming need for more frequent and thorough dental care for CSHCN and likely all children in the United States. Access to mental health services was not significant for the three groups, with a minor increase in unmet needs for children with ID compared with ASD. More research is needed to compare mental health diagnoses and overall needs between these three groups of children.

Insurance plays a role in children having their health care needs met (Fry-Bowers 2015, p. 212). Analysis showed that children with ID alone were less likely to have consistent health insurance coverage than those with ASD during the previous 12 months. This could play a major role in preventing children with ID from receiving all the medical care they require. Children with both diagnoses were less likely to have insurance that appropriately met their needs and allowed them to see a needed provider than children with ASD. The significant differences in insurance type are interesting to consider in the unmet insurance needs analyses, with children with ID and children with both diagnoses being more likely to have public insurance or a combination of public and private insurance, compared with children with ASD alone. There is lack of clarity explaining the differences preventing continuous coverage for children with ID only, given no significant difference in the family poverty level or parents' education level. Notably, this study did not assess parental employment status, which may impact insurance type as well. However, there could be a connection between lack of continuous insurance for children with ID and the increase in unmet health care needs. No difference was found between children with ID alone and children with ASD alone and whether the coverage met their needs or allowed them to see needed providers. A previous study of an NSCH survey (2009–2010) found that children with ASD were more likely to have inadequate insurance coverage compared with children with ID (Zablotsky *et al.* 2014, p. 399), but this study shows this is no longer the case. Cost or insurance issues are a significant barrier for children with developmental delays under the age of four to receive needed therapies (Magnusson *et al.* 2016, p. 149). Since CSHCN utilise the largest amount of paediatric health care services, having health insurance that is

consistent, affordable and adequate is vital to these children (Fry-Bowers 2015, p. 212).

Based on this study, there is clear evidence that children with ID or both diagnoses require a range of services, yet parents feel those needs are not being met. There are multiple potential reasons for these mismatches, including lack of appropriate insurance. In most European countries, with universal health insurance, insurance access and coverage is likely not as significant an issue. Given the restrictions in communication of many CSHCN with their parents or health care workers, there is potential that medical ailments that the child experiences may cause behaviours interpreted as being a mental health problem rather than a medical condition that is untreated (Menezes *et al.* 2021, pp. 2204–2205). The unmet mental health care needs in children with co-occurring ID and ASD result in a poorer quality of the overall health care received and interactions with health care workers (Menezes *et al.* 2021, pp. 2204–2205). Of concern is the idea that existing unmet needs for a child could result in poorer quality of health care provided due to a weak provider–patient relationship (Menezes *et al.* 2021, p. 2205). Special attention to the differences in needs, unmet care and access to this care, including insurance coverage, for children with ID alone is important. If a diagnosis of ASD provides enhanced access to health care not available to those with ID, potential inequities for CSHCN in the United States based on diagnosis must be considered. There is a more global concern that a government system enacting legislation to support a subset of a population with certain health care needs may be suppressing the needs and awareness of other groups with equally significant diagnoses.

The possibility that parents may not report all unmet health care needs during the NSCH warrants consideration. The question prompt in the NSCH, using a lead-in question of, 'During the past 12 months, was there any time when this child needed health care, but it was not received?' does not mention any specific barriers that could affect ability to get care, which could be interpreted by the reader as being unmet needs due to parent neglect (White *et al.* 2022, p. E158). The parent must also be able to consider what services would be needed for their child (Magnusson *et al.* 2016, pp. 145, 148). It is known that parents of CSHCN from vulnerable groups (e.g.

rural, impoverished, uninsured and African American), are less likely to identify unmet needs for health-related services due to limited access to quality health care (Mayer *et al.* 2005, p. 625).

Opportunities to improve health care delivered to CSHCN include increased accuracy of diagnostic tools and delivery of treatment by parents (Menezes *et al.* 2021, p. 2204). While paediatric health care workers do have more training and experience interacting with children with developmental disabilities, enhanced education and exposure, particularly for children with ID with or without ASD, may help decrease the number of unmet health care needs. Health care workers trained to treat adult patients have generally less knowledge and experience with individuals with developmental disabilities and could significantly improve the care received as CSHCN transition to adulthood. Strategies may include increasing coordinated care, especially in a family medical home while ensuring a child's access to insurance (Benevides *et al.* 2016, p. 886; Boudreau *et al.* 2014, pp. 1050–1052; Litt & McCormick 2015, pp. 188–189; Vohra *et al.* 2014, pp. 823–824). There are adjustments parents and health care providers can make to increase the ease of providing services to children. To decrease child and parent stress while completing a thorough and reliable audiological evaluation, visual supports such as videos can be used for CSHCN (McTee *et al.* 2019, p. 829). Completing in-school eye examinations with special education staff on hand can help with obtaining a comprehensive vision evaluation and allow children's teachers and parents to be on the same page, resulting in better health and education outcomes for CSHCN (Black *et al.* 2019, p. 16; McConnell *et al.* 2020, pp. 14–16). Incorporating an oral cavity exam into regular primary care check-ups can help introduce CSHCN to dentistry via desensitisation and familiarity (Delli *et al.* 2013, p. e867).

Due to the recent changes made to the NSCH before the 2016–2017 survey, comparisons of data from previous years' surveys cannot be carried out. It will be interesting, however, to compare the data from the 2016–2019 NSCH with any future surveys. Additionally, it may be possible to use this research to develop a tool for health care providers to assess the unmet needs of children with ID and ASD during routine visits and provide referrals or suggestions for ways to meet any unmet needs.

One potential confounder is that from a clinical perspective, once a child has a diagnosis of ASD made, the fact that they also have an ID might not be emphasised. There may be under-reporting of children with ID and ASD, if parents are unaware of the diagnosis of ID. This may affect the results of this study, and further research is needed to investigate this concern.

This study was a secondary analysis of a national survey dataset. Being a cross-sectional study, a major limitation is the lack of a true cause and effect relationship, making any associations difficult to interpret. Hence, incidence cannot be determined; only prevalence of a disease can be evaluated. The timing of the survey collection may not be always representative of the nation's population.

Conclusions

Children with ID alone are more likely to have unmet health care needs for medical, hearing and mental health care than children with ASD alone. Children with co-occurring ID and ASD are more likely to have unmet health care needs in general, but less likely to have unmet medical needs compared with children with ASD alone. This suggests children with ID, more so than those with ASD, have unmet basic health care needs, but the addition or lack of a diagnosis of ASD makes a difference. The likely reasons could be due to children with ID having more complex health care needs, as well as less consistent insurance, than children with ASD. A lack of consistent health insurance can hinder their ability to receive quality care. Children with ID are clearly being identified as meeting certain CSHCN criteria for additional services or needs, but this is not carrying through in practice. Further investigation is needed to determine what is preventing children with ID alone from accessing the care and resources they need.

This information will be helpful to health care providers and parents of children with ID and/or ASD. By understanding these unmet needs, providers and parents can develop resources for meeting children's health care needs. Additional research regarding differences in providers' treatment of children with ID compared with ASD, the availability of resources for differing diagnoses, and differences in

insurance coverage for all three groups of children may also increase understanding of the issues.

Acknowledgements

The authors would like to thank Joanna Anderson, Luzviminda Sinha, and Dr. Jonathan Thackeray for their assistance and advice during this process.

Source of funding

Open Access Funding is enabled by Wright State University.

Conflict of interest

The authors have nothing to disclose. No conflicts of interest have been declared.

Data availability statement

Data for this study were obtained from the Child & Adolescent Health Measurement Initiative (CAHMI), Data Resource Center for Child & Adolescent Health at childhealthdata.org/dataset. The data sets are not available from the corresponding author due to Data User Agreement restrictions. All National Survey of Children's Health data sets are publicly available from CAHMI upon direct request.

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Accepted 7 March 2022