Research Square

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# Neurodevelopmental condition count, functional difficulties, and care-coordination gaps among U.S. children with caregiver-reported congenital heart conditions: a cross-sectional NSCH study, 2020-2024

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## Abstract

# Background

Children with congenital heart disease often receive care across cardiology, primary care, developmental, rehabilitation, and educational services. We examined whether the number of current neurodevelopmental diagnoses and the number of functional difficulties were associated with care-coordination gaps among U.S. children with caregiver-reported congenital heart conditions.

# Methods

We analyzed pooled 2020–2024 National Survey of Children's Health data in a cross-sectional study of children aged 6–17 years. A congenital heart condition was defined by caregiver report of a heart condition that was present at birth. The primary outcome was failure to receive at least one needed element of effective care coordination among children who needed coordination. Survey-weighted modified Poisson models estimated adjusted prevalence ratios (aPRs) for neurodevelopmental condition count and age-applicable functional difficulty count, each categorized as 0, 1, or 2 or more.

# Results

Among 3,830 children meeting the congenital heart condition definition, 2,788 needed care coordination and had a classifiable outcome. The weighted prevalence of care-coordination failure in this domain was 40.8% (95% confidence interval [CI], 37.1%-44.6%). In separate models, both condition count and functional difficulties were associated with higher failure prevalence. In the joint model, neurodevelopmental estimates included the null, whereas functional difficulties remained associated with failure (one difficulty: aPR, 1.77; 95% CI, 1.37–2.28; 2 or more difficulties: aPR, 2.31; 95% CI, 1.78–3.01). The same pattern was present after restriction to children with a current heart condition.

# Conclusions

Functional difficulties identified children whose caregivers reported more gaps in needed care coordination. Assessment of everyday function may add useful information when services span medical, developmental, rehabilitation, and educational settings.

## Background

Congenital heart disease (CHD) is a lifelong condition with consequences that often extend beyond the cardiovascular system. Neurodevelopmental difficulties can persist through childhood and adolescence, and current guidance recommends longitudinal surveillance, evaluation, referral, and management [1]. Primary care guidance likewise emphasizes communication among families, primary care clinicians,

cardiologists, and other specialists [2]. Reviews of neurodevelopmental follow-up programs describe multidisciplinary care pathways that link developmental assessment with medical and educational services [18].

Care becomes harder to coordinate as the number of involved services grows. Children with heart conditions may receive cardiology and primary care while also using developmental, rehabilitation, behavioral, educational, or other specialty services. In the 2016–2017 National Survey of Children's Health (NSCH), fewer than half of children with parent-reported heart conditions met criteria for a medical home, and care coordination was less frequently achieved than among children without a reported heart condition [3].

Diagnosis count and functional difficulty describe different parts of this service burden. A diagnosis identifies a condition, whereas a functional difficulty describes its effect on daily activities and participation. In broader populations of children with special health care needs, functional limitation has been associated with greater service use, unmet health care needs, family time spent coordinating care, and poorer care-coordination experiences [4, 17, 19]. National studies have documented variation in unmet coordination needs across clinical and sociodemographic groups [5, 6] and associations between care coordination and access to specialty or supportive services [7, 8].

Beginning in 2020, the NSCH public-use files distinguish caregiver-reported heart conditions that were present at birth from other heart conditions. We used pooled 2020–2024 data to examine whether the number of current neurodevelopmental diagnoses and the number of functional difficulties were associated with failure to receive all needed care coordination among children who needed it. We also examined component questions about additional coordination help and the settings in which communication gaps occurred.

## Methods

# Study design and data source

We conducted a secondary cross-sectional analysis of the 2020-2024 enhanced NSCH topical public-use files. The NSCH is an annual, nationally representative survey of noninstitutionalized U.S. children aged 0-17 years living in households; one child is randomly selected within each sampled household for an age-specific topical questionnaire [9,10]. Enhanced files were used consistently across the five survey years. Reporting followed the STROBE recommendations for cross-sectional studies [15].

The five annual files contained 254,309 records. For pooled analyses, the selected-child weight was divided by five so weighted totals represented an average annual population during 2020-2024. Sampling strata combined state and the released STRATUM variable, and household identifier HHID was specified as the primary sampling unit, following Census Bureau guidance for multi-year NSCH analysis [11]. The full pooled survey file was retained for variance estimation, and analytic populations were specified as

survey subpopulations. Core variables and age applicability were checked in each annual file; Supplementary Table S5 summarizes the cross-year availability of the analysis constructs [20].

# Study population

Children were eligible if they were 6-17 years old, a caregiver reported that the child currently or previously had a heart condition (HEART), and the caregiver reported that the heart condition was present at birth (HEART_BORN). This definition identifies caregiver-reported congenital heart conditions. It does not provide an anatomical diagnosis. A total of 3,830 children met the definition. The primary outcome analysis included children who needed care coordination and had a classifiable effective care-coordination outcome (N = 2,788; Fig. 1).

# Care-coordination outcome and component analyses

The primary outcome was failure to receive all needed elements of effective care coordination. We reconstructed the Child and Adolescent Health Measurement Initiative (CAHMI) Effective Care Coordination component of the medical home measure using S4Q01, K5Q20_R, K5Q21, K5Q22, K5Q30, K5Q31_R, and K5Q32 [13,20]. The algorithm classifies children as not needing coordination, receiving all needed components, or not receiving one or more needed elements. The binary primary outcome compared the latter two groups among children who needed coordination. The reconstruction reproduced the published CAHMI national unweighted category counts for the 2022 and 2023 survey years.

K5Q21 asks whether the family could have used extra help arranging or coordinating the child's care. We analyzed this item as a component-based supplementary outcome rather than an independent validation of the composite. K5Q22, which asks how often the family received as much help as wanted, and the provider, help, and school communication components were summarized descriptively.

# Neurodevelopmental condition count

We counted six current caregiver-reported diagnoses: attention-deficit/hyperactivity disorder, autism spectrum disorder, learning disability, speech or language disorder, developmental delay, and intellectual disability. A diagnosis was counted when the caregiver reported both a history of the diagnosis and that the condition was current. The count was categorized as 0, 1, or 2 or more. Children with at least two confirmed current diagnoses were assigned to the highest category even when another item was unresolved; classification as 0 or 1 required all six item statuses to be known.

# Functional difficulty count

Functional difficulties followed the age-applicable structure of CAHMI NSCH Indicator 1.10 [14]. For children aged 6-11 years, the count included reported difficulty with breathing, swallowing, stomach or bowel function, physical pain, memory or concentration, walking or climbing stairs, dressing or bathing, hearing, and vision. For children aged 12-17 years, doing errands alone was also included. Observed difficulties were counted when at least one age-applicable item was available; the count was missing only when every applicable item was unavailable. The final categories were 0, 1, or 2 or more difficulties.

# Covariates

Prespecified covariates were age group (6-11 or 12-17 years), sex, race and ethnicity, family income-to-poverty ratio, highest household education, insurance type, survey year, current caregiver-reported heart-condition status and severity, family structure, Census region, and household language. The models also included a binary count indicator for at least one of seven listed noncardiac physical or syndromic conditions: current allergies, current asthma, blood disorder, cerebral palsy, cystic fibrosis, Down syndrome, and current epilepsy or seizure disorder. Covariates were selected before model fitting to describe conditional associations across demographic, socioeconomic, and health-related factors; they were not selected by statistical significance.

# Statistical analysis

Survey-weighted percentages and 95% confidence intervals (CIs) described the analytic domain and unadjusted outcome prevalence. Because care-coordination failure was common, adjusted associations were estimated with Poisson regression using a log link and survey-design-based linearized variance estimates. Results are reported as adjusted prevalence ratios (aPRs) with 95% CIs [16]. Model 1 included neurodevelopmental condition count and all covariates; model 2 included functional difficulty count and all covariates; model 3 included both exposure measures and the same covariates.

The NSCH releases family income-to-poverty ratio as six multiply imputed implicates (FPL_I1-FPL_I6). Each implicate was analyzed and estimates were combined using Rubin's rules [12]. The primary analysis used complete cases for other covariates; 2,616 of 2,788 children (93.8%) were included in the joint model. Supplementary Table S6 reports item missingness. No a priori power calculation was performed because all eligible records in the five public-use files were included.

Adjusted prevalence estimates in Fig. 2 were obtained from survey-weighted logistic models using the same covariate set as model 3, followed by marginal standardization. These estimates show absolute probabilities; the aPR models remained the primary inferential analysis. Figure 3 displays the aPRs from models 1-3. A prespecified sensitivity analysis restricted the sample to children with a current heart condition and replaced the three-level cardiac-status covariate with current mild versus current moderate or severe status. Component-based K5Q21 models used the model 3 covariate set. Analyses were conducted in Stata/MP 18 (StataCorp, College Station, TX, USA).

## Results

# Study population

Among 254,309 pooled NSCH records, 3,830 children aged 6-17 years met the study definition of caregiver-reported congenital heart condition. Of these, 1,021 did not need care coordination and 21 had missing or unclassifiable coordination status. The primary domain therefore included 2,788 children, of whom 1,104 had at least one gap in needed coordination (Fig. 1). Among children in this domain, the weighted prevalence of care-coordination failure was 40.8% (95% CI, 37.1%-44.6%). The three-state distribution among all children with classifiable coordination status is shown in Supplementary Fig. S1.

Within the primary domain, 53.2% of children had no current neurodevelopmental diagnoses, 16.9% had one, and 29.9% had 2 or more. For functional difficulties, 42.1% had none, 22.4% had one, and 35.5% had 2 or more. Children aged 12-17 years represented 53.6% of the weighted population; 43.1% had no current heart condition, 43.0% had a current mild condition, and 13.9% had a current moderate or severe condition (Table 1).

# Care-coordination failure by exposure level

Care-coordination failure increased across categories of both exposure measures. Weighted failure prevalence was 32.6% among children with no current neurodevelopmental diagnoses, 48.3% among those with one diagnosis, and 51.3% among those with 2 or more diagnoses. The corresponding prevalences across functional difficulty categories were 26.4%, 42.9%, and 56.6% (Table 2).

# Adjusted associations

In model 1, one current neurodevelopmental diagnosis was associated with a higher prevalence of care-coordination failure compared with no current diagnoses (aPR, 1.39; 95% CI, 1.10-1.76); the estimate for 2 or more diagnoses was 1.52 (95% CI, 1.24-1.86). In model 2, the aPR was 1.74 (95% CI, 1.36-2.22) for one functional difficulty and 2.30 (95% CI, 1.83-2.89) for 2 or more difficulties compared with none (Table 3; Fig. 3).

When both exposure measures were included in model 3, the neurodevelopmental estimates moved toward the null (one diagnosis: aPR, 1.09; 95% CI, 0.87-1.36; 2 or more diagnoses: aPR, 1.05; 95% CI, 0.84-1.31). Functional difficulties remained associated with care-coordination failure (one difficulty: aPR, 1.77; 95% CI, 1.37-2.28; 2 or more difficulties: aPR, 2.31; 95% CI, 1.78-3.01).

# Adjusted prevalence

Standardized predicted prevalences from the joint covariate set were 39.7% (95% CI, 34.1%-45.2%), 43.7% (35.2%-52.3%), and 41.6% (35.1%-48.2%) across 0, 1, and 2 or more neurodevelopmental diagnoses. The corresponding estimates across functional difficulty categories were 24.9% (19.6%-30.2%), 44.2% (37.3%-51.0%), and 58.1% (50.7%-65.4%) (Fig. 2).

# Component and sensitivity analyses

Among 2,714 children with valid K5Q21 responses, caregivers of 17.0% (95% CI, 14.4%-19.6%) reported that they could have used additional help coordinating care. In the adjusted component model (N = 2,544), the aPRs were 1.03 (95% CI, 0.64-1.66) for one current neurodevelopmental diagnosis and 1.61 (95% CI, 1.10-2.38) for 2 or more diagnoses. For functional difficulties, the aPRs were 2.89 (95% CI, 1.83-4.55) for one and 3.92 (95% CI, 2.48-6.22) for 2 or more (Supplementary Table S2).

Among 485 children whose caregivers reported that additional help could have been useful and who answered K5Q22, 18.7% usually received as much help as wanted, 45.0% sometimes did, and 36.3% never did (Supplementary Table S3). Descriptive analyses found gaps in communication among doctors or providers (38.0%), receipt of needed coordination help (32.4%), and communication with schools, child care, or special-education services (28.0%) within their respective applicable populations (Supplementary Table S4).

Restriction to children with a current heart condition produced the same joint-model pattern. The aPRs for functional difficulties were 1.55 for one difficulty and 2.22 for 2 or more difficulties; the corresponding neurodevelopmental estimates were 1.07 and 0.99 (Supplementary Table S1).

# Discussion

Care-coordination gaps were common among children with caregiver-reported congenital heart conditions who needed coordination. Neurodevelopmental condition count and functional difficulty count were each associated with higher failure prevalence when examined separately. In the joint model, the neurodevelopmental estimates included the null, whereas functional difficulties retained a graded association with coordination failure. Restricting the analysis to children with a current heart condition produced a similar pattern.

Diagnosis count and functional difficulty capture related aspects of a child's needs. A diagnosis records a clinical label; functional questions describe the effects of health problems on daily activities. Earlier studies of children with special health care needs linked functional limitation to greater service use, unmet needs, and care-coordination problems [4,17]. The attenuation of the neurodevelopmental estimates after joint adjustment may reflect overlap in the needs captured by the two measures. The cross-sectional data cannot distinguish shared burden from a pathway in which neurodevelopmental conditions contribute to functional difficulty.

The distinction matters for CHD care because developmental needs often persist beyond cardiology visits. Guidelines call for longitudinal surveillance and referral [1,2], and follow-up programs commonly rely on multidisciplinary teams and links with educational services [18]. In this study, functional difficulty was associated with coordination gaps after accounting for current caregiver-reported heart-condition status, other listed health conditions, and measured social factors. Functional information may therefore help care teams recognize families whose services cross several settings.

The component findings describe where these gaps arise. Caregivers reported difficulty obtaining coordination help and communicating across clinicians and schools. These items are part of the composite outcome and clarify its content. Broader NSCH research has shown that caregivers of children with more complex special health care needs spend substantial time coordinating care and that heavier coordination demands are linked to forgone care [19]. National studies have also linked care coordination with access to specialty and supportive services [7,8].

The primary estimand applies to children whose caregivers indicated a need for care coordination. The three-state description in Supplementary Fig. S1 shows that the proportion classified as not needing coordination declined as diagnosis count and functional difficulty increased. This context is important because the binary outcome does not describe children who were outside the need-defined domain.

All key health and coordination measures were caregiver reported, and the survey does not provide anatomical diagnosis, surgical history, or physiologic detail. The same reporter assessed functional difficulties and coordination experiences, which may contribute to correlated reporting. The cross-sectional design does not establish temporal order, and the joint model estimates conditional associations rather than mediation. Complete-case analysis retained 93.8% of the primary domain; residual bias from item nonresponse remains possible. The pooled national survey, survey-design-based analyses, agreement with published CAHMI category counts, and current-heart-condition sensitivity analysis support the consistency of the main association pattern.

## Conclusions

Among U.S. children aged 6-17 years with caregiver-reported congenital heart conditions who needed care coordination, functional difficulties were associated with more gaps in receiving needed coordination. Neurodevelopmental condition count was associated with failure in separate models, but its estimates moved toward the null when functional difficulties were included. Routine attention to everyday function may improve service planning when a child's care spans medical, developmental, rehabilitation, and educational settings.

## Abbreviations

aPR: adjusted prevalence ratio; CAHMI: Child and Adolescent Health Measurement Initiative; CHC: congenital heart condition; CHD: congenital heart disease; CI: confidence interval; FPL: family income-to-poverty ratio; NDD: neurodevelopmental disorder; NSCH: National Survey of Children's Health; PSU: primary sampling unit; STROBE: Strengthening the Reporting of Observational Studies in Epidemiology.

## Declarations

# Ethics approval and consent to participate

This secondary analysis used publicly available, de-identified NSCH public-use data. Institutional review board approval and informed consent were not required for this analysis.

# Consent for publication

Not applicable.

# Availability of data and materials

The public-use NSCH datasets analyzed in this study are available from the U.S. Census Bureau NSCH data portal [9]. All aggregate results supporting the findings are included in this article and its supplementary information.

# Competing interests

The authors declare that they have no competing interests.

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# Authors' contributions

WD performed the analyses, prepared the figures and tables, and drafted the manuscript. MX supervised the study, acquired funding, and reviewed and edited the manuscript. Both authors read and approved the final manuscript.

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# Tables

**Table 1. Weighted characteristics of the primary analytic domain**

| Characteristic | Category | Unweighted n | Weighted % |
|---|---|---|---|
| Care-coordination outcome | Received all needed coordination | 1684 | 59.2 |
| | Did not receive ≥1 needed element | 1104 | 40.8 |
| Neurodevelopmental condition count | 0 current NDDs | 1468 | 53.2 |
| | 1 current NDD | 408 | 16.9 |
| | ≥2 current NDDs | 866 | 29.9 |
| Functional difficulty count | 0 functional difficulties | 1198 | 42.1 |
| | 1 functional difficulty | 658 | 22.4 |
| | ≥2 functional difficulties | 932 | 35.5 |
| Age group | 6-11 years | 1213 | 46.4 |
| | 12-17 years | 1575 | 53.6 |
| Sex | Male | 1497 | 52.1 |
| | Female | 1291 | 47.9 |
| Race/ethnicity | Hispanic | 391 | 23.6 |
| | Non-Hispanic White | 1901 | 55.0 |
| | Non-Hispanic Black | 182 | 12.0 |
| | Non-Hispanic Asian | 77 | 1.4 |
| | Non-Hispanic other/multiracial | 237 | 8.0 |
| Family income-to-poverty ratio | <100% | — | 15.5 |
| | 100-199% | — | 24.1 |
| | 200-399% | — | 28.6 |
| | ≥400% | — | 31.7 |
| Highest household education | Less than high school | 44 | 5.2 |
| | High school | 321 | 18.2 |
| | More than high school | 2423 | 76.6 |
| Insurance type | Public only | 734 | 32.2 |
| | Private only | 1671 | 53.1 |

| Characteristic | Category | Unweighted n | Weighted % |
|---|---|---|---|
| | Private and public | 273 | 10.1 |
| | Uninsured | 74 | 4.5 |
| Survey year | 2020 | 472 | 16.2 |
| | 2021 | 484 | 20.0 |
| | 2022 | 613 | 21.1 |
| | 2023 | 561 | 18.7 |
| | 2024 | 658 | 23.9 |
| Current cardiac status/severity | No current heart condition | 1221 | 43.1 |
| | Current mild | 1188 | 43.0 |
| | Current moderate/severe | 364 | 13.9 |
| Other listed physical or syndromic conditions | No other listed condition | 1293 | 46.0 |
| | ≥1 other listed condition | 1470 | 54.0 |
| Family structure | Two biological/adoptive parents, married | 1688 | 55.7 |
| | Other two-parent household | 313 | 14.2 |
| | Single-parent household | 631 | 25.3 |
| | Grandparent/other household | 112 | 4.8 |
| Census region | Northeast | 456 | 14.0 |
| | Midwest | 689 | 23.4 |
| | South | 838 | 40.8 |
| | West | 805 | 21.9 |
| Household language | English | 2657 | 91.2 |
| | Non-English | 112 | 8.8 |

The primary analytic domain included 2788 children who needed care coordination and had a classifiable outcome. Percentages are survey weighted and are calculated among available observations; denominators for non-FPL variables vary because of item nonresponse. FPL estimates combine the six official NSCH implicates, so unweighted category counts are not shown. FPL, family income-to-poverty ratio.

**Table 2. Care-coordination failure by condition count and functional difficulties**

| Exposure | Category | Unweighted n | Failures | Weighted failure % (95% CI) |
|---|---|---|---|---|
| Neurodevelopmental condition count | 0 current NDDs | 1468 | 459 | 32.6 (28.0-37.2) |
| | 1 current NDD | 408 | 165 | 48.3 (37.3-59.4) |
| | ≥2 current NDDs | 866 | 465 | 51.3 (44.6-58.0) |
| Functional difficulty count | 0 functional difficulties | 1198 | 308 | 26.4 (21.4-31.5) |
| | 1 functional difficulty | 658 | 275 | 42.9 (35.8-50.1) |
| | ≥2 functional difficulties | 932 | 521 | 56.6 (49.6-63.6) |

The primary analytic domain included 2788 children. Failure was defined as not receiving at least one needed element of care coordination among children who needed coordination. Forty-six children with a missing neurodevelopmental condition count were excluded from that exposure-specific distribution; functional difficulty count was classifiable for all 2788 children. Percentages and 95% CIs account for the NSCH complex survey design. CI, confidence interval; NDD, neurodevelopmental disorder.

**Table 3. Adjusted prevalence ratios for care-coordination failure**

| Model | Comparison | aPR (95% CI) |
|---|---|---|
| M1 NDD count | 1 current NDD vs 0 | 1.39 (1.10-1.76) |
| M1 NDD count | ≥2 current NDDs vs 0 | 1.52 (1.24-1.86) |
| M2 Functional difficulties | 1 functional difficulty vs 0 | 1.74 (1.36-2.22) |
| M2 Functional difficulties | ≥2 functional difficulties vs 0 | 2.30 (1.83-2.89) |
| M3 Joint | 1 current NDD vs 0 | 1.09 (0.87-1.36) |
| M3 Joint | ≥2 current NDDs vs 0 | 1.05 (0.84-1.31) |
| M3 Joint | 1 functional difficulty vs 0 | 1.77 (1.37-2.28) |
| M3 Joint | ≥2 functional difficulties vs 0 | 2.31 (1.78-3.01) |

The reference category was 0 for each exposure. M1 included neurodevelopmental condition count; M2 included functional difficulty count; M3 included both. All models adjusted for age group, sex, race/ethnicity, FPL, household education, insurance, survey year, current caregiver-reported heart-condition status and severity, other listed physical or syndromic conditions, family structure, Census region, and household language. FPL estimates combined six official NSCH implicates. M1 and M3 included 2616 children and 1030 failure events; M2 included 2656 children and 1045 events. aPR, adjusted prevalence ratio; CI, confidence interval; FPL, family income-to-poverty ratio; M, model.

# Figures

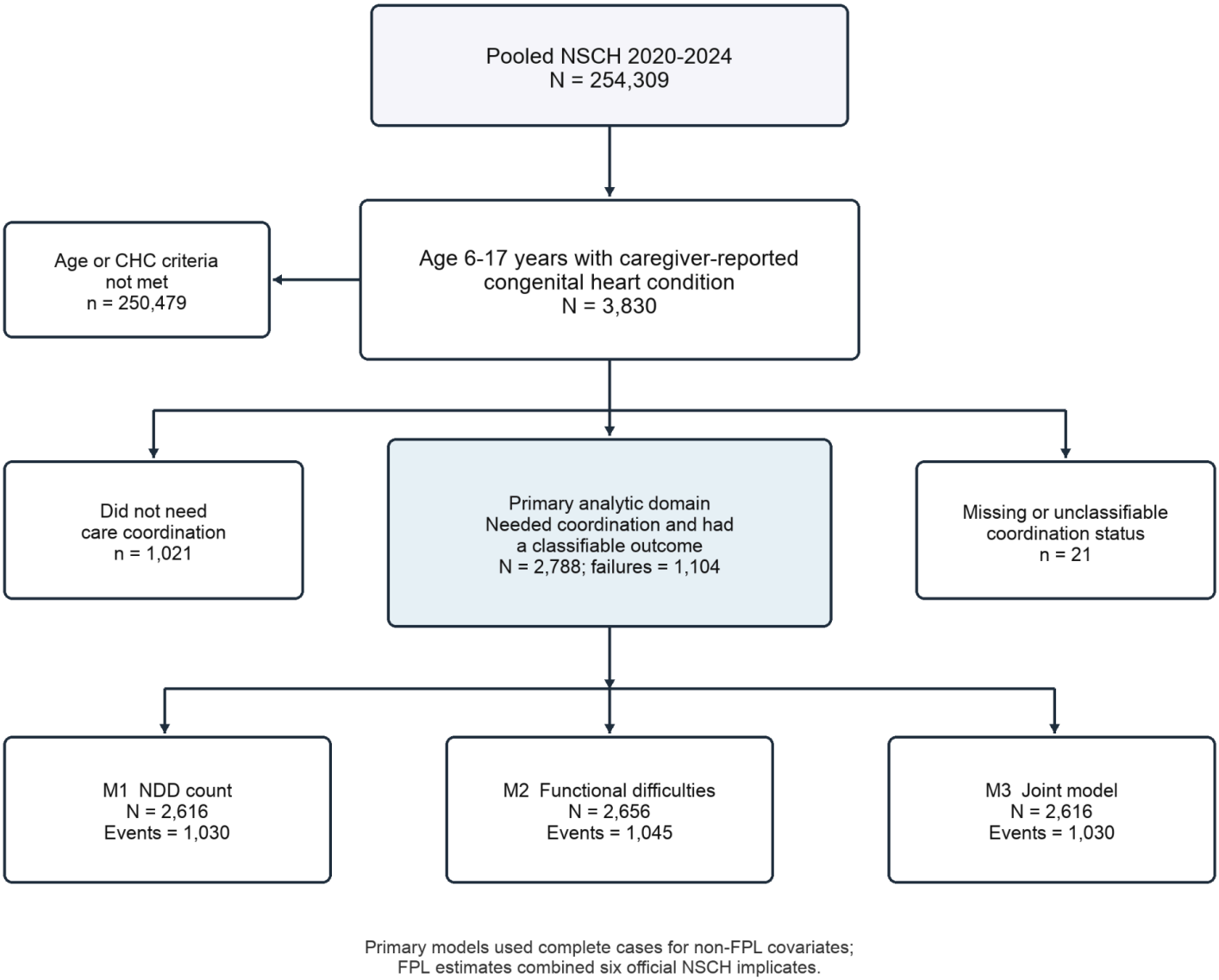
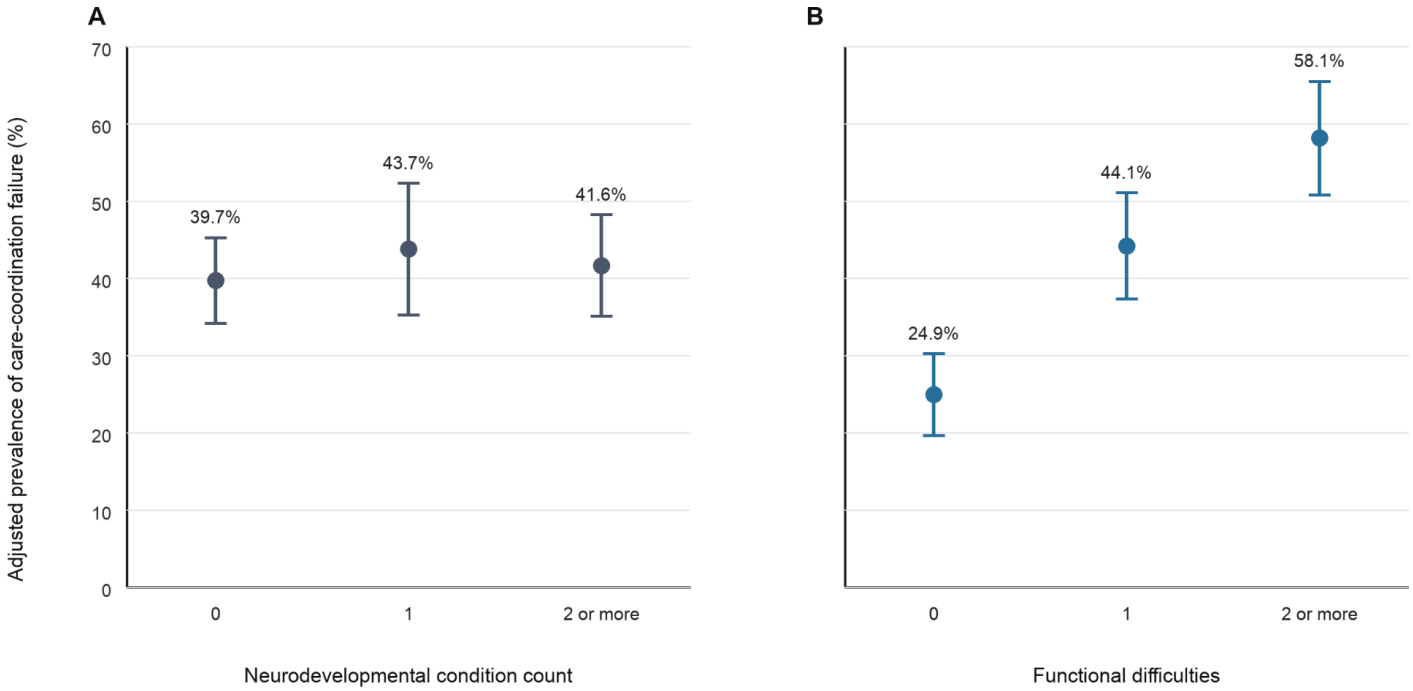



**Figure 1**

**Study population and analytic samples**

The pooled file contained 254309 records. CHC was defined by caregiver report of a heart condition that was present at birth. Of 3830 children aged 6-17 years who met this definition, 1021 did not need care coordination and 21 had a missing or unclassifiable coordination status. The primary domain included 2788 children who needed coordination and had a classifiable outcome. Primary models used complete cases for non-FPL covariates; FPL estimates combined six official NSCH implicates. CHC, congenital heart condition; FPL, family income-to-poverty ratio; M, model; NDD, neurodevelopmental disorder; NSCH, National Survey of Children's Health.




## Figure 2

### Adjusted prevalence of care-coordination failure

Survey-weighted marginally standardized predicted probabilities of care-coordination failure from logistic models using the joint covariate set (n = 2616). Panel A shows estimates by neurodevelopmental condition count; panel B shows estimates by functional difficulty count. Models adjusted for age group, sex, race/ethnicity, FPL, household education, insurance, survey year, current caregiver-reported heart-condition status and severity, other listed physical or syndromic conditions, family structure, Census region, and household language. Predictions were calculated separately within each official FPL implicate and combined using Rubin's rules. Points show predicted percentages and error bars show 95% CIs. CI, confidence interval; FPL, family income-to-poverty ratio.

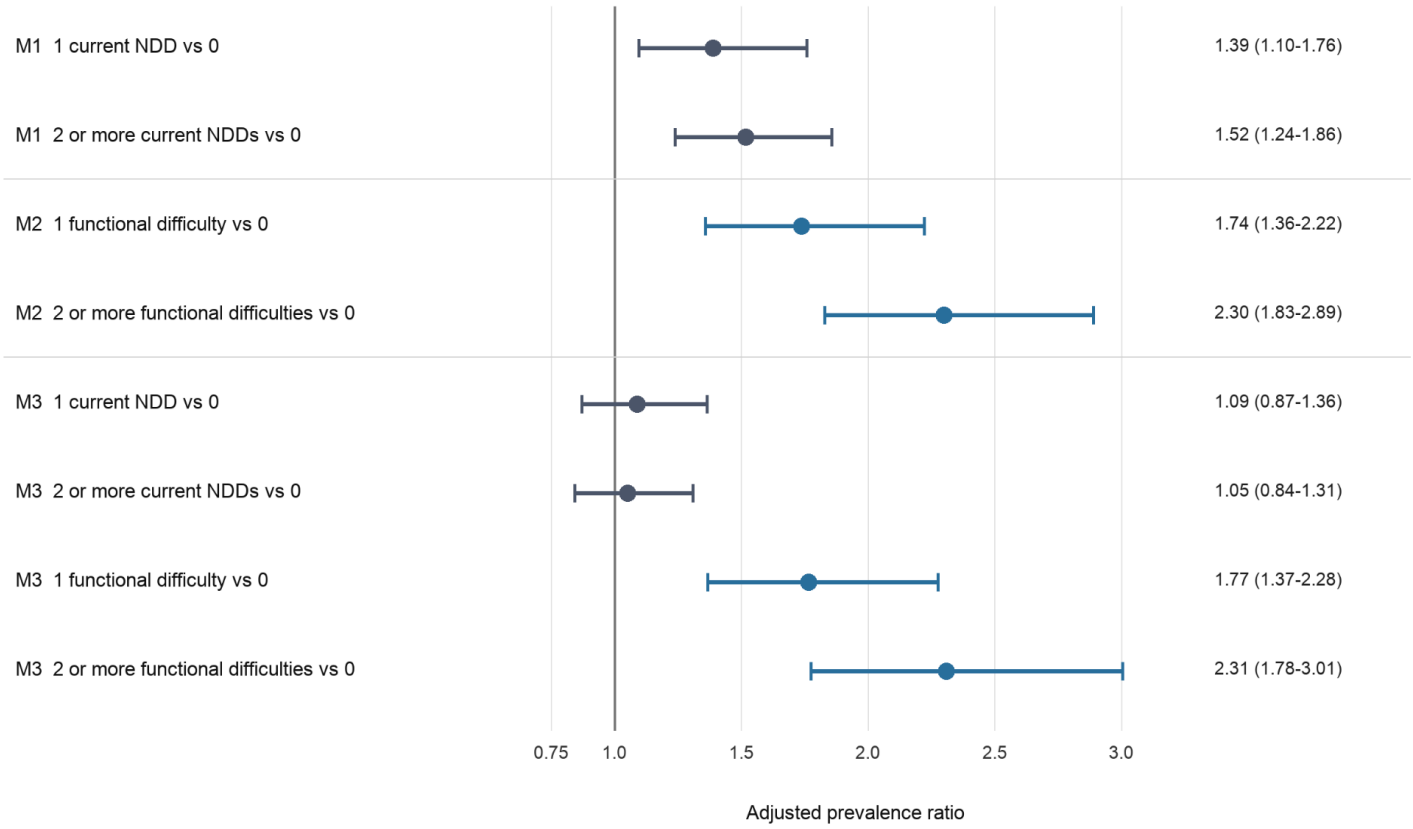



**Figure 3**

**Adjusted prevalence ratios across primary models**

Points show adjusted prevalence ratios and horizontal lines show 95% CIs; 0 was the reference category for each exposure. M1 included neurodevelopmental condition count (n = 2616; 1030 failure events), M2 included functional difficulty count (n = 2656; 1045 events), and M3 included both exposure measures (n = 2616; 1030 events). All models used the covariate set listed in Table 3. The vertical line indicates an aPR of 1. aPR, adjusted prevalence ratio; CI, confidence interval; M, model; NDD, neurodevelopmental disorder.

# Supplementary Files

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- BMCPediatricsCHC20202024Additionalfile1.docx