Establishing a protocol for building a pan-Canadian population-based monitoring system for early childhood development for children with health disorders: Canadian Children’s Health in Context Study (CCHICS)

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ABSTRACT

Introduction Health disorders early in life have tremendous impact on children’s developmental trajectories. Almost 80% of children with health disorders lack the developmental skills to take full advantage of school-based education relative to 27% of children without a health disorder. In Canada, there is currently a dearth of nationally representative data on the social determinants of early childhood development for children with health disorders. Evidence from Canada and other countries indicate that poorer developmental outcomes in typically developing children are associated with lower socioeconomic status (SES). However, to date, it is not known whether this relationship is stronger among children with health disorders. The study’s objectives are to estimate the prevalence and to investigate social determinants of developmental outcomes for young children with health disorders, using the Early Development Instrument (EDI).

Methods and analysis Study objectives will be achieved through three steps. First, using existing EDI data for 10 provinces and 2 territories collected from 2004 to 2015, we will investigate differences in developmental health outcomes among children with identified health disorders. Second, population-level EDI data will be linked with neighbourhood sociodemographic census data to explore associations between socioeconomic characteristics and rates of specific diagnoses among children aged 5–6 years, including trends over time. Third, for 3 of these 12 regions, additional health and/or education databases will be linked at an individual level. These data will be used to establish differences in EDI outcomes in relation to the age-of-onset of diagnosis, and presence of intervention or treatment.

Ethics and dissemination Study methodologies have been approved by the Hamilton Integrated Research Ethics Board. The results of the analyses of developmental health outcomes for children with health disorders combined with SES will have implications for both health service delivery and school-based intervention strategies. Results will contribute to a framework for public policy.

Strengths and limitations of this study

- Canadian Children’s Health in Context Study will use population-level pan-Canadian data to monitor the developmental health of over 990,502 children, of which 155,838 have a health disorder.
- This study offers a broad overview of the developmental health vulnerabilities of children with health disorders across Canada, as well as over time, which allow for in-depth analyses of the social determinants of health.
- Linkages at the individual level between child development data and health and/or education administrative data in three provinces will allow for the exploration of factors contributing to the association between developmental health outcomes and SES.
- Asynchronous data collection cycles in provinces may be a limitation.
- Health disorders may be subject to over-reporting or under-reporting, which may differ by type of disorder or place of residence, therefore limiting interpretation.

INTRODUCTION

Early childhood trajectories

According to Unicef, healthy development is a right for every child.1 A health disorder that is, a diagnosable medical condition early in life, has a tremendous impact on the developmental health trajectory of a child. Among otherwise healthy children, approximately one in four kindergartners (27%) lacks the developmental skills to take optimal
advantage of school-based education. Among children with identified special health needs at that age, this proportion rises to almost 80%. Having a health disorder in childhood often impacts trajectories of development throughout childhood, adolescence and adulthood. For instance, poor physical, mental and socioemotional development in childhood is linked to later school failure, unemployment, delinquency and poor health in adulthood. Accordingly, providing additional support to children who are struggling can have protective effects that can set the child on a healthier trajectory, provided we are able to identify those at risk. In environments rich with developmental opportunities and positive experiences, young children can flourish, regardless of their impairment, disease or health condition. Recent advances in understanding the developmental outcomes for children with health disorders indicate that difficulties are often confined to the areas of disability, and, most importantly, that it is possible to experience a healthy developmental trajectory within a context of a health disorder.

Children’s health and socioeconomic gradients

The constellations of conditions in which children are born and grow are often referred to as social determinants of health. Social determinants of health include, among other things, income, social status, education, social support networks as well as social and physical environments. It has long been recognised that socioeconomic status (SES), usually conceptualised as a combination of income, education and employment indicators, is strongly related to health, with lower SES associated with both higher mortality and morbidity. While not synonymous with social determinants, SES is one of their strongest correlates. The disparities in health across SES are referred to as the socioeconomic gradient, underscoring that difference in health outcomes is gradual and occurs across the full spectrum of SES. That is, individuals living in poverty have poorer outcomes when compared with those at the top of the SES hierarchy, but each increase in income is associated with an increase in positive outcomes. The gradient in health status across SES has been well described across a variety of conditions in both adult and child populations. Differences in SES at younger ages are particularly important for setting lifetime health trajectories.

There is emerging evidence that low SES can negatively affect the speed of brain development. In this regard, societal inequities are likely to exert a stronger impact on children with health disorders than on those growing up without health disorders, henceforth referred to as ‘typically developing’. Families of children with health disorders are also more likely to experience socioeconomic disadvantage. Combined with additional social or economic risks (eg, single parent family, low income), health disorders can significantly increase a child’s odds for later negative outcomes.

SES gradient may affect children with health disorders differently than typically developing children. Current research on children with health disorders has explored the association of SES factors with prevalence or with outcomes (such as academic achievement or behaviour), but not both, and usually for no more than one disorder/diagnosis at a time. This gap has been acknowledged in particular in the emerging paediatric literature focusing on children with special healthcare needs, as it limits comparability, and thus implications for further research and policy. Research in three Canadian provinces has shown that substantive differences in developmental health among typically developing children at school entry are tied to SES, and even less about whether this relationship is similar for children with health disorders.

Measuring child development at the population level

Until recently, Canada has lacked nationally representative data pertaining to social indicators of children’s developmental health at school entry. Data collection initiatives implemented across most Canadian provinces and territories over the past decade have sought to address this gap, using the Early Development Instrument (EDI) to monitor trends in children’s development across jurisdictions. The EDI is a teacher-completed checklist that measures children’s developmental health at school entry in kindergarten in five domains: physical health and well-being, social competence, emotional maturity, language and cognitive development and communication skills and general knowledge. It has been administered at the population level in most Canadian provinces and territories since 2004 (table 1). EDI data are collected for each child individually and then aggregated at various levels to offer an assessment of developmental vulnerability in a given population. While the main purpose of the EDI is the assessment of child development, the questionnaire includes information on children’s special needs, functional difficulties and as of 2010, diagnoses. Participants with any of these comprise the sample of children with health disorders in the dataset. This approach reflects the non-categorical concept of illness.

A population-level database of developmental outcomes in kindergarten (as measured by the EDI) has recently been created in a project funded by the Canadian Institutes of Health Research (CIHR), referred to as the Canadian Neighbourhoods and Early Childhood Development (CanNECD) study. The aim of the CanNECD study was to establish a pan-Canadian database for monitoring children’s developmental health and well-being. This database merged pan-Canadian EDI data from 2004 to 2015, spanning 12 of the 13 Canadian provinces and territories, with the Canadian 2005 and 2010 Taxfiler data, as well as 2006 Census and 2011 National Household Survey data using children’s postal codes.
The primary goal of the current study, named the Canadian Children’s Health in Context Study (CCHICS), is to investigate the impact of different health disorders diagnosed prior to kindergarten and socioeconomic disadvantage on children’s developmental outcomes at school entry. Analysis of these data will provide an opportunity to interpret and disseminate findings on developmental outcomes and socioeconomic gradients at regional and provincial levels for children with different health disorders. CCHICS aims to establish the prevalence of health disorders and explore the social determinants of developmental outcomes for children with health disorders. CCHICS is guided by the following research questions:

1. For children diagnosed with health disorders, how do their developmental health outcomes, measured with the EDI in kindergarten, differ from those of typically developing children, and do they vary depending on the type of disorder?

2. What is the association between prevalence rates of various health disorders in kindergarten and neighbourhood-level SES? Does this association vary across jurisdictions (e.g., provinces, health regions)?

3. What is the association between developmental outcomes as measured by the EDI and SES for children with health disorders? Is it the same as for children without health disorders?

4. In three provinces with the capacity to link EDI to administrative health and education data at the individual level (Manitoba, British Columbia (BC), Ontario), what are the factors contributing to the association between EDI outcomes and SES?

Table 1  Canadian Early Development Instrument implementation schedule from 2003/2004 to 2014/2015 with percentages and number of children with health disorders, as well as number of typically developing children for each implementation

| Year      | AB  | BC  | MB  | NB  | NL  | NT  | NS  | ON  | PEI | QC  | SK  | Y   |
|-----------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| 2003/2004 | 13% | 13% | 13% | 9%  |     |     | 13% |     |     |     |     |     |
| 2004/2005 | 18% | 13% | 13% | 9%  |     |     | 13% | 15% | 229 | 1291|     |     |
| 2005/2006 |     | 18% | 16% |     |     |     |     | 15% | 2158| 9513|     |     |
| 2006/2007 | 12% | 10% | 12% | 9%  |     |     | 10% |     |     |     |     |     |
| 2007/2008 |     | 20% | 12% | 12% |     |     |     |     |     |     |     |     |
| 2008/2009 | 20% | 12% |     |     |     |     |     |     |     |     |     |     |
| 2009/2010 | 19% |     |     |     |     |     |     |     |     |     |     |     |
| 2010/2011 | 20% |     |     |     |     |     |     |     |     |     |     |     |
| 2011/2012 | 16% |     |     |     |     |     |     |     |     |     |     |     |
| 2012/2013 |     |     |     |     |     |     |     |     |     |     |     |     |
| 2013/2014 |     |     |     |     |     |     |     |     |     |     |     |     |
| 2014/2015 |     |     |     |     |     |     |     |     |     |     |     |     |

Light blue cells indicate a partial provincial collection. Dark blue cells indicate a full provincial collection. If the dark blue box spans multiple years, it means a province or territory completed the implementation in waves.
Table 2 Domains and subdomains of the Early Development Instrument

| Domains                        | Subdomains                                      |
|--------------------------------|-------------------------------------------------|
| Physical health and well-being | Physical readiness for the school day            |
|                                | Physical independence                           |
|                                | Gross and fine motor skills                    |
| Social competence              | Overall social competence                       |
|                                | Responsibility and respect                      |
|                                | Approaches to learning                         |
|                                | Readiness to explore new things                 |
| Emotional maturity             | Prosocial and helping behaviour                 |
|                                | Anxious and fearful behaviour                   |
|                                | Aggressive behaviour                            |
|                                | Hyperactivity and inattention                   |
| Language and cognitive         | Basic literacy                                  |
|                                | Interest in literacy/numeracy and memory        |
|                                | Advanced literacy                               |
|                                | Basic numeracy                                  |
| Communication skills and       | Communication skills and general knowledge      |
| general knowledge              |                                                 |

METHODS AND ANALYSIS

Data sources and variables

Developmental health at school entry data

The EDI is a measure of developmental health of kindergarten-age children, implemented at population levels in most jurisdictions in Canada. It is a 103-item, teacher-completed survey of five domains of children’s development: physical health and well-being; social competence; emotional maturity; language and cognitive development and communication skills and general knowledge, further broken down into 16 subdomains (table 2). Variables relevant to the research objectives are: age, sex, special needs status, functional impairments, a specific diagnosis, if any, and the mean scores for each (sub)domain. After receiving training, kindergarten teachers complete the EDI in the second half of the school year. The psychometric properties of the EDI have been extensively validated. The EDI is a reliable and cost-efficient method of assessing developmental health outcomes at the developmentally critical period of transition to school and has moderate-to-high predictive validity for later school achievement. The EDI is completed for each individual student and the results are aggregated to a group level (according to geographic or demographic criteria) for interpretation. The most common aggregations are at the neighbourhood, school district and province/territory levels. The Offord Centre for Child Studies (OCCS), at McMaster University, is the national repository of the anonymised EDI data.

Derived measures. Health disorders. On the EDI, teachers report on whether a child has a limitation that interferes with their ability to function in the classroom, with 11 categories provided (box 1), and whether or not he/she has a special need.  Developmental health. Mean scores for each of the five EDI domains, and for the 16 EDI subdomains will be used. Vulnerability on each domain, that is, a score below the 10th percentile based on the population sample of over 160 000 Canadian kindergarten children, will also be used, in addition to overall vulnerability (0=not vulnerable, 1=vulnerable), which represents vulnerability in at least one of the five domains. For each aggregate unit of analysis (eg, neighbourhood, school district), child-level data are aggregated to represent the ‘percentage of vulnerable children’ overall, and in a domain, for the given unit of analysis.

The EDI database contains data for over 990 502 kindergarten children, of whom 155 858 (15.7%) have either an identified special need (yes/no), a functional impairment (out of 11) or a diagnosis (up to 3 out of a possible 37; see table 3) of a health disorder. The newly developed linkage between EDI and databases containing neighbourhood-level sociodemographic variables offers an opportunity to investigate the degree of impact of socioeconomic disadvantage on children with health disorders. Furthermore, the linking of the individual records from the EDI–SES databases with existing health and educational administrative databases in 3 out of the 12 jurisdictions will allow us to replicate and validate, on a subsample, the robustness of the patterns found for population-level data, by including health diagnoses occurring after kindergarten, treatment and service data, and individual-level indicators of SES.

Neighbourhood-level socioeconomic status

The measures of neighbourhood-level SES applied in this study are based on the methodology established for the CanNECD study. Socioeconomic and demographic information will come from the 2006 Canadian Census and 2011 National Household Survey, as well as the 2005 and 2010 Taxfiler data. Geographic regions have been established for the CanNECD study. The criteria and boundaries maintain existing geographical, social and neighbourhood boundaries, where possible.

The traditional conceptualisations of SES usually rely on indicators of income, education and occupation, and these will be used in our models, following the establishment of a new SES index for the CanNECD study. Building on the methodology in the CanNECD study, additional SES and demographic indicators will be used in the analyses, including measures of wealth, poverty, lone parenthood, unemployment, residential dwelling/type of housing, residential stability, occupation, education, immigration and language diversity.

Individual-level health/education data linkages

For three provinces, provincial EDI datasets will be linked with other population-wide databases at the individual level. Different combinations of data sources (eg, health,
| Diagnosis                                                                 | Code |
|---------------------------------------------------------------------------|------|
| Mental health                                                             |      |
| ADHD                                                                       | 1    |
| Anxiety                                                                   | 2    |
| Depression                                                                | 3    |
| Oppositional defiant disorder/conduct disorder                            | 4    |
| Other mental health disorders                                             | 5    |
| Developmental disabilities                                               |      |
| Autism spectrum disorder (includes autism, Asperger syndrome and pervasive developmental disorder not otherwise specified) | 6    |
| Developmentally delayed/global delay                                      | 7    |
| Down syndrome/other genetic developmental disability                      | 8    |
| Fetal alcohol spectrum disorder or alcohol-related neurodevelopmental disorder | 9    |
| Intellectual delay (mild or moderate)                                     | 10   |
| Rett’s disorder, childhood disintegrative disorder                        | 11   |
| Learning disorders (reading, writing, math)                               | 12   |
| Speech and language disorders                                             |      |
| Apraxia                                                                   | 13   |
| Cleft palate/lip                                                          | 14   |
| Receptive or expressive language                                          | 15   |
| Selective mutism                                                          | 16   |
| Other speech and language disorders                                       | 17   |
| Sensory disorders                                                         |      |
| Blind/visually impaired                                                   | 18   |
| Deaf/hard of hearing                                                      | 19   |
| Other sensory                                                             | 20   |
| Motor disorders                                                           |      |
| Cerebral palsy                                                            | 21   |
| Mitochondrial disease                                                     | 22   |
| Muscular dystrophies                                                      | 23   |
| Spina bifida                                                              | 24   |
| Other motor impairment                                                    | 25   |
| Other                                                                     |      |
| Acquired brain injury                                                     | 26   |
| Asthma                                                                    | 27   |
| Cancer/leukaemia/brain tumour                                             | 28   |
| Cystic fibrosis                                                           | 29   |
| Diabetes                                                                  | 30   |
| Epilepsy/seizures                                                         | 31   |
| Heart problems/stroke                                                     | 32   |
| Juvenile rheumatoid arthritis                                            | 33   |
| Obesity                                                                   | 34   |
| Phenylketonuria/other metabolic                                            | 35   |
| Roulette syndrome                                                         | 36   |
| Other, not listed                                                         | 37   |
The individual-level linkages in Manitoba will occur at MCHP and analyses will be conducted by one of their analysts. CCHICS researchers will only receive results and will not have access to the linked data. As for the linkages in BC and Ontario, the various establishments will link and deidentify the data before providing access to the local CCHICS investigators.

**Analysis plan**

The planned analyses are designed to address each of the research questions outlined above. The statistical analyses will take place once the databases have been prepared (EDI/SES) or access approved (individual-level databases). Building on the methods developed for the CanNECD study, we will statistically model the additive and multiplicative associations between the SES and demographic variables and developmental outcomes for children with health disorders. Results of these analyses will be particularly valuable for research dissemination and knowledge translation purposes for specific regions, and within different health disorder subpopulations, as they will allow, for the first time, the ability to explore SES-related factors that are associated with positive development outcomes for children with health disorders.

**Research question 1**

*Developmental outcomes in kindergarten for children with health disorders.* The health information reported on the EDI will be used to create several groups. First, the typically developing reference group will be identified, comprising children without any diagnosed health disorders, special needs or functional impairments. Second, the health disorder group will be identified as children with any diagnosed health disorder, special needs or functional impairments. This group will be further subdivided into those with specific disorders (eg, autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), cerebral palsy (CP), etc) and categories of disorders (eg, mental health, developmental delay, speech and language, etc). Where possible with administrative databases, the conditions will be categorised using the International Statistical Classification of Diseases and Related Health Problems 10th Revision. The analyses will focus on EDI scores at the domain-level and subdomain-level as outcomes. Diagnostic subgroups of children with specific disorders (eg, ASD, ADHD, CP, etc) will be compared with the reference group and then with each of the other groups (ie, ASD compared with ADHD, and so forth). We will also compare children with only a diagnosis to those with a diagnosis and either a second diagnosis, a special needs designation, teacher-reported functional concerns or all of the above.

**Research question 2**

*Association of the prevalence of health disorders and SES.* Our analyses aim to identify the combinations of SES factors that are most strongly associated with the prevalence of health disorders for: (1) the pan-Canadian context, (2)
different regions (ie, provincial, health regions, neighbourhoods) and (3) with various subpopulations and health groups (eg, boys compared with girls, ASD vs other developmental disorders, single vs comorbid disorders, etc). The association between the identified SES factors and prevalence (overall prevalence and prevalence of specific disorders) will be tested for main and interaction effects, after controlling for the child-level variables (gender, age, English as a second language) available from the EDI. The first model to be tested will be that of the selected SES variables and the prevalence of health disorders. Next, the multiplicative associations of the SES variables will be added to the model. Finally, child-level variables and geographic-unit variables will be added to the model as covariates at the different levels of clustering. These analyses will be performed for each province/territory in the study.

Research question 3
Child developmental outcomes and SES indices. We will statistically model associations between the SES composite indicators and developmental health outcomes using EDI vulnerability rates for each of the five domains, as well as overall vulnerability rates, for children with health disorders in order to replicate the findings for typically developing children. The relationship between the SES index variables identified in the CanNECD study and the EDI mean scores for children with health disorders will also be examined,42 and the most strongly correlated neighbourhood-level SES index variables will be used as neighbourhood-level covariates. The relationship between the SES variables and each of the outcomes will be tested for main and interaction effects. These analyses will be repeated for each jurisdiction and each disorder with an adequate sample size.

Research question 4
Case study provinces: impact of timing of diagnosis and presence of comorbidities on the association between outcomes and SES. For three provinces (BC, Manitoba and Ontario), children’s EDI data will be linked at an individual-level with administrative health and education databases, which include diagnostic information and age of onset of first diagnosis. These data will be used to search for unique behaviour functioning characteristics, measured by the EDI, among children who were, for the respective disorders, first diagnosed at a relatively younger or older age, and those with comorbidities (ie, for children with more than one disorder). The availability of individual-level measures of poverty in BC and Manitoba will also allow us to determine whether the patterns observed using area-level measures of SES are replicated at the individual level.37 As with research question 3, we will statistically test the main and interaction effects between SES factors and EDI overall vulnerability rates, including the interaction between SES and age of diagnosis, and (separately) the interaction between SES and the existence of comorbidities.

Ethics and dissemination
Participant confidentiality is protected as the EDI, Census and Taxfiler data for this study are aggregated to the neighbourhood level and hosted in a secure database system.

The team of investigators maximises the relevance of the findings to different communities of practice (academic, clinical, education and policy) and the reach to diverse health-oriented groups. Currently, results from each EDI implementation are disseminated to participating communities and school districts and have been incorporated by governments and agencies as an indicator of children’s health and well-being.52 53 We have a large network of collaborators from other universities and jurisdictions, whose interests intersect with our programme and may, at an appropriate time, join the team of investigators. Relationships are already well established with many study stakeholders (eg, clinicians and educators) through various relationships of the investigators. This will facilitate mobilisation of the knowledge generated through this research and translate it to various audiences (eg, clinicians, educators, policy-makers, researchers, community groups and parents) through four major mechanisms: practitioner/community networks, education and knowledge dissemination networks, policy-makers and data accessibility.

DISCUSSION
Few data sources provide the opportunity to researchers to examine the combined association between early childhood health disorder and socioeconomics in relation to children’s early developmental outcomes. CCHICS is a novel approach to do so at a pan-Canadian population level. As such, it will generate new knowledge, which will contribute to the science of child development, and will be of immediate use and application in community contexts. The sociodemographic neighbourhood factors associated with the prevalence of particular disorders that we expect to find will support public health community efforts to improve access and integration of early identification services in neighbourhoods. The integrated knowledge base resulting from this project will establish: (1) a population-based prevalence of health disorders by jurisdiction, thus allowing future monitoring of health and developmental trajectories of children with these disorders; (2) the extent to which socioeconomic disadvantage affects developmental outcomes for children with health disorders; (3) the degree of impact of SES on child development for different types of health disorders and (4) the factors that contribute to the mechanism of association between SES and development that can contribute to our understanding of interventions and supports for children with health disorders.

In this study, our goal is to identify SES and social factors, if any, that contribute to ‘unfair and unnecessary
inequities’ in children’s developmental health outcomes for those with health disorders. Identifying these inequities is the first step towards developing strategies to flatten the socioeconomic gradients. By flattening these gradients, we can improve the overall health status of children, so that society can move towards the goal of achieving equity from the start. Our research will allow us to compare social gradients across jurisdictions, health disorder subgroups and groups with associated functional impairments. Our pan-Canadian data allow for comparisons that would be otherwise impossible due to small frequencies of specific health disorders in any given jurisdiction, and if each province or territory had their own, incommensurable indicator of developmental health outcome. Moreover, population-level data, and specifically EDI data, have guided action and progress towards improving early childhood development in Canada and Australia, and have transformed early childhood systems in parts of the USA. Our methodology and findings will have instant relevance to research in these countries, as well as others that use EDI data on a regular basis.

This approach of examining children with health disorders will also help contribute new knowledge and make meaningful differences at a policy level, as well as for children in the classroom. Despite scattered evidence of educational and health sectors adopting policies reflecting the growing knowledge about actions that will assist in optimising developmental outcomes (eg, introduction of full-day learning in Ontario and BC, enhanced billing codes for the 18 month well-baby visit in Ontario), provincial policy innovation is inconsistent across Canada, and there is no federal policy framework for the early years. The results of our study, with their direct relevance to early identification and detection policies, both in the health and education sectors, have a high potential for a direct impact on policies supporting optimal development for children with health disorders.

**Limitations**

Despite many advantages (such as geographic breadth and sample size), our study has limitations. With the exception of the administrative databases in Manitoba, BC and Ontario, the diagnostic information is based on parent information, not on administrative diagnostic codes. Health disorders may be subject to over-reporting or under-reporting, which may differ by type of disorder or even place of residence. These limitations will be addressed by exploring concordance between EDI and health databases in Manitoba, BC and Ontario. However, until data are available to researchers in the remaining provinces, these limitations cannot be easily overcome in population-based studies. Another potential limitation is the small number of cases of certain disorders, which may limit the analyses possible by the SES indicators, and by the five EDI domains and 16 subdomains; aggregation of measures may be necessary in these cases. In addition, our definition of ‘primary’ diagnosis as the first listed disorder is somewhat arbitrary and may require additional sensitivity analyses. Finally, it is important to note that while this study uses the neighbourhood-level SES to examine the impact of sociodemographic factors on child development, it does not commit the ecological fallacy as it does not make inferences about the individual children’s SES based on neighbourhood SES.

**CONCLUSION**

CCHICS offers an important opportunity to investigate developmental outcomes in children at risk that are not commonly included or available in sufficient numbers in sample-based research on children with health problems. This study also provides a unique and timely opportunity to use existing resources and methods to monitor the prevalence of health disorders at a population level. Establishing the pattern of the SES gradient is needed for designing early interventions, for policy-level decision-making regarding the type and location of services, and for understanding the necessary conditions for optimal developmental trajectories of children with health disorders.

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