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Publicly-Available Data and Pediatric Mental Health: Leveraging Big Data to Answer Big Questions for Children

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There's nothing new about "big data;" the term was coined in 1997 by researchers who were struggling to process the massive volumes of data required for visualization of complex fluid dynamic models (Cox & Ellsworth, 1997). However, in biomedical and behavioral research, our thinking about big data has undergone a major revolution in recent years, with vast volumes of research data being made available to researchers, clinicians, and the public. In 2011, the National Institutes of Health (NIH) launched its Big Data to Knowledge (BD2K) initiative with the purpose of leveraging existing data to answer new questions about human health and behavior (National Institutes of Health, 2015). Yet definitions of big data are vague, even on the BD2K website, and the means of finding, accessing, analyzing, and leveraging big data remain obscure to many researchers and clinicians. One thing that all definitions seem to agree upon is that big data poses both incredible promise and unique challenges. Publicly-available big data are especially well-suited to answering questions about the mental health of children, as these rich data sets allow investigation of multiple influencing factors while strictly protecting the confidentiality of participants through de-identification. This article will highlight these benefits and challenges, describe some key pediatric data sets, and discuss how big data might be used to help predict, prevent, or treat pediatric mental health problems.

The Benefits of Publicly-Available Data

Publicly-available big data provides a range of substantial benefits to researchers and clinicians with questions about clinical problems. These benefits vary across studies based on design, sample size, and type of data collected, but all publicly-available data share one major benefit: *ease of access*. Many providers of publicly-available data require only that

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users register with their website in order to obtain the data, while others allow direct download without registration, making the data available not just to researchers, but also to the public.

Timeliness is another major benefit, particularly for longitudinal data that an individual researcher might spend years or decades collecting. With publicly-available data, the time frame from hypothesis to evidence is shortened because the data are already collected, cleaned, coded, and de-identified. Codebooks, methodology documentation, sample characteristics, analytic strategies, and sample weighting strategies are generally made available by the data providers. Additionally, publicly-available data that is pre-existing and de-identified generally falls under institutional review board (IRB) exemption, thus speeding up the review process.

Nationally representative sampling is another strength of many publicly-available data sets. Sample weighting allows data sets with oversampled subsets to become representative of the larger population. In addition, sample sizes are much larger than those typically feasible for an individual research team to collect. Large sample sizes enable the use of more advanced statistical methods such as multilevel modeling, structural equation modeling, and propensity score matching, all of which improve our understanding of the interrelatedness of concepts and our ability to make causal inferences (Stuart, 2010) about topics that cannot be examined with randomized controlled trials. These advanced methods provide stronger support than simple correlations for targeted intervention research and clinical practice change.

Cost, efficiency, and ethical considerations are interrelated concepts that must be addressed when discussing big data. By their nature, these data are already collected and many are available as no-cost or low-cost alternatives to researchers during funding gaps or as preliminary evidence to shore up grant applications. Perhaps more importantly, the efficient use of such data is an important consideration, given the limited resources available for research. This efficiency of use is further supported by the ethical duty of researchers to participants, who have generously given their time, information and sometimes biological samples for the express purpose of addressing important research questions. Failure to use these data efficiently may expose others to risks, even if minimal, that are ethically unacceptable if the research could have been carried out from pre-existing data.

Challenges for Researchers and Clinicians

While the benefits of publicly-available big data are substantial, a few challenges and limitations also exist. Because of the nature of big data, *specialized statistical expertise* is usually required in order to ensure that the appropriate methods and interpretations are used. Sample weights provided serve to control statistical bias associated with measuring a small subset of a larger population by adjusting the sample pool to more closely match the larger population on a number of characteristics (Solon, Haider, & Wooldridge, 2015). Good weighting strategies improve the generalizability of observational data, but these require some expertise to handle appropriately. Null hypothesis tests of significance, such as ANOVA and *t*-tests, rely in part on sample size to determine statistical power (Lomax &

Hahs-Vaughn, 2012). In very large samples with thousands or even hundreds of thousands of participants, these types of statistics may report statistical significance where no clinical significance exists because the size of the sample simply overpowers the tests. To counter this, the inclusion of effect size determinants both in interpretation of the findings and in reporting is needed. In addition, care must be taken to insure that the data meet the assumptions of the statistical methods that are used. Many data sets are provided in multiple statistical package formats, however some are provided only in one format or are suggested for use with a particular software package. For these reasons, collaboration with a statistician or methodologist who is familiar both with big data sets and sample weighting is highly recommended.

Measurement may also pose a challenge to researchers looking to leverage big data. Specifically, as study designs are predetermined by others, the “ideal” measure of a construct or phenomenon may not have been used to generate the data. Researchers and clinicians attempting to answer clinical questions may have to familiarize themselves with unfamiliar tools and measures or they may need to consider alternative data sets, all of which may require additional researcher time and effort. While some big data collection teams welcome input from “outside” researchers about additional measures and collaborative data collection for future data collection periods, others do not allow researchers to add measures or collect additional data, limiting the type of questions that can be asked.

Finally, with few exceptions, publicly-available data are *observational*, meaning they are often inappropriate for answering research questions about interventions. While statistical methods such as propensity score matching may improve the ability of researchers to make causal inference (Stuart, 2010), the observational nature of these data may simply offer insight into areas for future research.

Publicly-Available Data with Children’s Mental Health Measures

An ever-increasing number of data sets are available that contain measures, survey questions, and assessments on children’s growth, development, physical health, and behavioral and mental health. Examples of how big data has already made a big difference for children can be seen in use in pediatric practices around the nation. Pediatric growth charts were originally established and are regularly updated using data from the National Health and Nutrition Examination Survey (NHANES) which completes comprehensive biological, health, and survey examinations on 5,000 people every year, a subset of whom are children (Centers for Disease Control and Prevention, 2013). The NHANES data has also provided prevalence figures for pediatric diseases and national recommendations on nutrition, and has driven policy changes that led to a national reduction in blood lead content in children through the elimination of lead in gasoline (Centers for Disease Control and Prevention, 2013).

When it comes to pediatric mental health, however, the use of big data has lagged somewhat behind. NHANES includes a number of measures of pediatric mental health, but PubMed searches in June 2014 with the terms “NHANES” and “children” returned fewer than 300

results when paired with “mental health”, yet over 3,000 results when paired with the terms (obesity or weight). Table 1 illustrates the key factors of four publicly-available data sources that include mental health and behavioral measures for children. Of these example studies, two are ongoing, longitudinal studies and two use cross-sectional samples in multiple data waves, each with unique participants. All of these big data sets contain demographic information and at least some measure of mental health or behavior.

For example, the Fragile Families and Child Wellbeing Study is a joint venture between researchers at Princeton University and Columbia University originally constructed to enable study of the influence of child welfare and paternal support policies on child wellbeing (Center for Research on Child Wellbeing, 2015). The currently available public data includes measures of cognition and survey data about school performance, social behaviors, and mental health on 4,898 children followed longitudinally from birth through age 9, with a retention rate above 70%. This rich body of data is linked to demographic information, social policy information, parental health and incarceration data, and neighborhood characteristics. Additional data including data extracted from medical records about the child’s birth, selected genetic markers, school characteristics, and geographical codes are available for restricted use with IRB approval and a nominal fee. Ongoing research by the study group is currently collecting data about the children at age 15 and will reportedly include genetic and biological measures as well as updated survey data. Researchers have previously used these data to address research questions related to the effects on children of parental incarceration, nonresident fathers, racial disparities, and exposure to violence (Center for Research on Child Wellbeing, 2015).

Conclusion

Big data sets offer a wealth of information that has formed the basis for our understanding of and practice around child health for decades. Some researchers have already begun addressing questions about child mental health from these data, yet much of the potential power of these data sets remains to be tapped. With the growing prevalence of complex pediatric mental health problems and the serious effects that these problems have on quality of life throughout the lifespan, a host of clinical and research questions have sprung up which demand prompt answers. Big data, and publicly-available data in particular, offer researchers and clinicians a pathway to addressing these questions about child mental health rapidly, cheaply, ethically, and in a way that supports wide generalizability. More information about big data and health care is available through the BD2K website (<https://datascience.nih.gov/bd2k>, National Institutes of Health, 2015) and at the Data.gov website (data.gov, 2015).

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Table 1

Examples of publicly-available data with children and mental health measures

	Add Health – The National Longitudinal Study for Adolescent to Adult Health	The Fragile Families and Child Well-Being Study	NHANES – The National Health and Nutrition Examination Survey	NSCH – The National Survey of Children's Health
Population	Nationally-representative sample of a cohort of people who were adolescents in 1994–1995	Nationally-representative of non-marital births in the United States	Nationally-representative sample	Nationally-representative of children ages 0–17 years.
Design	Longitudinal with currently available data in four waves [‡]	Longitudinal with currently available waves at birth, 1-year, 3-years, 5-years, 9-years [‡]	Annual cross-sectional	Cross-sectional surveys of parents with children aged 0–17 years.
Sample Size	20,745 adolescents in initial wave	4,898 families (dyads and triads) in the initial wave	5,000/year	Varies by wave, 2011/2012 data contain ~97,000
Original Purpose	Combines data on physical and psychological health with social contextual factors	To study the effects of child welfare and paternity policy on child well-being	Each year focuses on specific health measures	Characterize multiple aspects of children's health and lives
Cost of Access	No cost; no registration required, restricted-use data also available with registration	No cost for publicly-available data, \$250 registration fee for additional, restricted-use data; register at website	No cost; Direct download, no registration required, restricted-use data also available with registration	No cost; email data request form or browse data online with no registration required
Website	http://www.cpc.unc.edu/projects/addhealth	http://www.fragilefamilies.princeton.edu/index.asp	http://cdc.gov/nchs/nhanes.htm	http://childhealthdata.org/learn/NSCH
Mental Health and Behavioral Measures	Adolescent/study adult self-report, parent-report	Child self-report, parent interviews, teacher interviews	Varies	Parent-report survey
Survey Data	Yes [‡]	Yes [‡]	Yes	Yes
Biological Measures	Yes [‡]	Not yet available [‡]	Yes	No
Anthropometric Measures	Yes [‡]	No	Yes	No
Genetic Data	No	Restricted [‡]	Restricted	No

[‡] Indicates ongoing data collection in longitudinal studies