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Article Summary:

This report describes SARS-CoV-2 surveillance testing models for schools of children with intellectual and developmental disabilities and medical complexity during the COVID-19 pandemic.

Contributors' Statement

Mr. Sherby drafted the initial manuscript, collected data, carried out the initial analyses, and reviewed and revised the manuscript.

Drs. Coller, Foxe, Freedman, and Gurnett conceptualized and designed the study, coordinated and supervised data collection, drafted the initial manuscript, and reviewed and revised the manuscript.

Drs. Kalb, Demuri, Butteris, Zand, Dewhurst, and Newland conceptualized and designed the study, coordinated and supervised data collection, and critically reviewed the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

ABSTRACT

Children with intellectual and developmental disabilities (IDD) and children with medical complexity (CMC) have been disproportionally impacted by the COVID-19 pandemic, including school closures. Children with IDD and CMC rely on schools for a vast array of educational, therapeutic, medical, and social needs. However, maintaining safe schools for children with IDD and CMC during the COVID-19 pandemic may be difficult due to the unique challenges of implementing prevention strategies, such as masking, social distancing, and hand hygiene in this high-risk environment. Furthermore, children with IDD and CMC are at a higher risk of infectious complications and mortality, underscoring the need for effective mitigation strategies. The goal of this report is to describe the implementation of several screening testing models for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in this high-risk population. By describing these models, we hope to identify generalizable and scalable approaches to facilitate safe school operations for children with IDD and CMC during the current and future pandemics.

Importance of Schools for Children with Intellectual and Developmental Disabilities and Children with Medical Complexity

Children with intellectual and developmental disabilities **(**IDD) and children with medical complexity (CMC) have unique needs that must be considered when planning current and future pandemic responses. Approximately 14% of all public school students have some form of (IDD) [National Center for Education Statistics, May 2020].[1] Children with IDD are a heterogeneous group with cognitive and adaptive limitations. Common diagnoses of children with IDD include learning disabilities, speech and language impairment, autism spectrum disorders (ASD), intellectual and developmental delays, and emotional disturbances, such as anxiety and behavioral challenges. An added challenge is the range of abilities, from functional independence to complete dependence on life-supporting therapies, such as ventilators, gastrostomy tubes, or healthcare assistants.[2] While there is growing information about the safety of schools for typically developing children during the evolving COVID-19 pandemic,[3, 4] very little is known about the safety of schools for children with IDD who may not be able to follow mitigation

strategies against severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, such as masking, hand hygiene, and social distancing.

Health Risks of SARS-CoV-2 Infection for Children with IDD and CMC

Children with IDD are more vulnerable to SARS-CoV-2 infections, are at an extreme risk for severe symptoms if infected, and have a higher fatality rate (1.6%) compared with other children (<0.1%).[5] Their heightened risk for infection and mortality may result both from the child's underlying medical condition and from socioeconomic effects and other barriers limiting access to health care.[5] Their increased vulnerability is compounded by their difficulty with verbal communication, which can lead to the underreporting of symptoms, such as muscle aches, fatigue, and difficulty breathing. Additionally, their cognitive impairment and mobility issues may lessen compliance with safety protocols, such as distancing, masking, and sanitization. As a result, people with IDD of all ages are more than twice as likely to be diagnosed with COVID-19 compared with their peers.[5]

Pediatric populations with complex medical needs require increased attention to remain healthy. CMC routinely require complex medical care and are at an even higher risk of infection and complications from SARS-CoV-2 compared with other children.[6] CMC generally have one or more chronic conditions associated with medical fragility, causing substantial functional limitations, a high use of health care resources, and increased health care costs.[7, 8] While CMC comprise 1-5% of children, they account for more than 33% of total child health spending,[9] with the majority being for hospital care.[7] Many medical fragility patients have compromised

immunological and respiratory function that places them at a high risk for severe COVID-19 disease, including hospitalization and death.[10]

The health risks of the COVID-19 pandemic are also compounded by social determinants of health. CMC are a socially vulnerable population in the U.S., with over half of CMC with higher medical complexity living in poverty, 17% residing in rundown housing, and 14% being food insecure—all substantially higher than non-CMC.[11] The intersectionality of race, ethnicity, and disability places many individuals at a heightened risk of severe COVID-19 disease as a consequence of systemic race-based disparities.

Indirect Impact of the COVID-19 Pandemic on Children with IDD and CMC

Beyond the elevated direct risk that SARS-CoV-2 infection poses to children with IDD and CMC, these children and their families have been disproportionately impacted by school closures caused by the pandemic.[12] Many children access not only educational services in their school setting, but also social services, speech and physical therapy, psychological interventions, nutritional support, and medical care, including many CMC who require pulmonary care, further risking infection from aerosolized particles. For many of these children, this support is only available through school.[13] During the COVID-19 pandemic, parents and guardians of children with disabilities reported being overburdened because of the need to take on additional roles that school previously provided (eg physical therapy).[12] Pandemic-associated school closures have resulted in potentially catastrophic disruptions in the lives of these children and their families.

For parents and guardians, the burden of homecare is enormous, such that maintaining employment is often impossible when the child is out of school. These families were already stretched thin before the pandemic, as parents/guardians of children with IDD reported more parenting stress than those of typically developing children.[14] Parents of children with IDD, already disproportionately unemployed due to their children's care needs, experience added employment strain when their child is out of school. During the pandemic, caregivers of children with ASD further reported higher levels of burden, stress, anxiety, and depression compared with caregivers of typically developing children.[15] Parents of children with special needs are also less likely to be equipped to continue the child's learning remotely, further exacerbating their educational disadvantage.[16]

Children with IDD are at a greater risk for mental health symptoms than their neurotypical peers.[16-18] Dramatic changes in lifestyle, including pandemic-related fears, may disproportionally affect children with IDD. For instance, Vasa et al. (2021) found more than half of children with ASD in an outpatient setting had worsening of psychiatric symptoms over the pandemic.[19] Severe IDD impairs one's ability to engage with online educational platforms. School closures, with the loss of accompanying social and support systems, is one explanation for these findings. Continued school closures over multiple years have the potential to further isolate and compound social and health disparities for children with IDD.

Risks to Educators

The risks of conducting in-person school are not restricted to the children attending special schools. Schools for children with disabilities are complicated environments that include content specialists, in addition to educators, who converge to provide care throughout a typical day or week. Some CMC also require aerosol-generating procedures at school, such as respiratory ventilation, which presents further risks of infection to staff.[20] Hesitancy to return to in-person school was common among staff providing face-to-face services to students, particularly prior to the availability of effective vaccines, but remains a serious concern with the emergence of viral variants, particularly because mitigation strategies are limited.[21] Aside from infectious risk to themselves and their families, school staff may be wary of the impact that a positive result of a colleague or student could have on their employment and livelihood. Contacts of students or school staff who test positive are required to quarantine for long periods of time, often without pay. Large class quarantines have resulted in staff shortages that place an even greater burden on those remaining in the classroom.

Challenges of COVID-19 Mitigation Strategies for Children with IDD and CMC

Children with IDD, particularly those with sensory issues that are common among children with ASD, often have challenges tolerating masks. However, behavioral intervention and instruction has been shown to be effective at increasing mask wearing compliance in these children.[22] In addition, at schools for children with IDD in St. Louis, Missouri, administrators reported 70% mask compliance among the students.[23] On the bus and in the classroom, children with IDD typically require close contact with teaching assistants who often cannot maintain more than a

few inches of social distance. When a child has more complex medical needs, such as requiring help with eating, there is simply no ability to distance or mask.

As of August 2021, vaccines targeting SARS-CoV-2 have not yet been approved for children <12 years of age. In addition, special barriers exist for children with IDD and CMC, including fear that a vaccine-induced fever could trigger seizures, the possibility of an inadequate immune response to vaccine, or undesirable side effects of vaccines that may be considered unacceptable by families of medically fragile children.

Collecting biological samples from children with IDD and CMC posed one of the largest challenges of implementing SARS-CoV-2 surveillance testing as a mitigation strategy. The school environment for children with IDD also poses barriers for widespread testing. Many specialty schools are centrally located, or otherwise distanced from the child's home district, and require children to ride buses to school and interact with bus drivers. Parents therefore have limited daily interactions with teachers or school administrators for communication about complex testing needs and assistance with sample collection. Furthermore, even when a sample may be obtainable from a student at home with parental assistance, bus drivers may be unwilling to accept test samples on the bus, potentially limiting participation in a school's testing program.

Opportunities for Research

Despite the mitigation challenges unique to children with IDD and CMC, it is essential that schools remain open in a manner that is safe for students with IDD and the staff who work in these schools. The three Rapid Acceleration of Diagnostics-Underserved Population (RADx-UP) Return-to-School projects described in this report propose several testing strategies to increase the safety of students and staff in schools for children with IDD and CMC. By addressing the unique challenges posed by the COVID-19 pandemic in the special school setting, we hope to understand the best strategies for safely returning this vulnerable population to school. Our ultimate goal is to develop generalizable and scalable approaches that can be disseminated rapidly to facilitate school opening.

Diagnostic Testing Approaches Employed in Schools

Special School District (SSD) of St. Louis County and Kennedy Krieger Institute (KKI) in Baltimore, Maryland. Investigators at the Washington University in St. Louis McDonnell Genome Institute (GTAC@MGI) developed a high-sensitivity diagnostic test to detect the SARS-CoV-2 virus directly from saliva, thus obviating the need for nasopharyngeal swabs that pose a barrier to student testing, particularly in students with IDD. The test requires 0.5 ml of saliva, which may be collected with a sponge or pipette for students who are unable to spit. The non-invasive nature of saliva collection also facilitates its use in community settings, such as schools, because it does not require special training to collect and minimizes aerosolization. The test is processed and run at GTAC@MGI on the Washington University in St. Louis campus with a run time of less than 3 hours, and results are returned to participants on the same day.

Through a commercial partnership with Fluidigm (San Francisco, California), the method was made publicly available and is now in use at other institutions.

Rochester, New York. The investigative team at the University of Rochester's Intellectual and Developmental Disabilities Research Center (UR-IDDRC) has partnered with a local specialized school, the Mary Cariola Center (MCC), which serves children with moderate-to-severe IDD (N=450) via a large professional and support staff (N=500). We have deployed a nasal mid-turbinate swab-based specimen collection tool, produced by ThermoFisher Scientific (Waltham, Massachusetts), known as the Amplitude Solution with TaqPath COVID-19 High-Throughput Combo Kit. A significant advantage of this specimen collection methodology is that it does not require the now infamous "brain scrape" associated with nasopharyngeal swabbing, common to many COVID-19 testing kits. The nasopharyngeal procedure likely contributes to substantial test apprehension in the general population[24] and presents even greater challenges in children with IDD who are often fearful and prone to movements. The simple nasal swab used here requires minimal training to collect and is not associated with significant discomfort. Students and staff enrolled in the study receive surveillance testing every 10 days on a rolling schedule, with additional on-demand testing provided to any participant who reports or is deemed symptomatic. Tests are delivered to the University of Rochester's Central Laboratory for testing in a CLIA environment with test results faxed to the Nurse Practitioner at Mary Cariola the following morning (12-24-hour turnaround times).

Madison, WI. Investigators at the University of Wisconsin-Madison are using the BinaxNOW Rapid Antigen System (Abbott Labs, Chicago, Illinois), a point-of-care, lateral flow immunoassay for the qualitative detection of SARS-CoV-2 nucleocapsid protein antigen using direct anterior nasal (nares) swabs in home or school settings. To collect a nasal swab sample, the entire absorbent tip of the BinaxNOW kit swab is inserted into both nostrils, then placed in the supplied card, and an extraction reagent is added. After 15 minutes, the results are read as the presence or absence of a blue line compared with the control line. Tests are repeated twice within 3 days, at least 36 hours apart, and positive tests are confirmed with PCR testing from a nasopharyngeal sample.

SCHOOL SETTINGS

St. Louis, MO and Baltimore, MD. This study leverages two geographically diverse school partners from Missouri and Maryland. The Special School District (SSD) of St. Louis County provides special education and related services for more than 23,000 kindergarten through 12th grade (K–12) students within 22 public school districts in St. Louis County. While the vast majority of students receive special education and related services at their home school in the district in which they live, 909 children with disabilities are educated in one of the District's six special education schools devoted to children with IDD. At these six schools, SSD employs 590 teachers, staff, and administrators. Children who attend these schools are bussed from their homes daily.

The School Programs at the Kennedy Krieger Institute provide private K–12 special education and related clinical services for students with IDD and significant behavioral challenges throughout Maryland and the DC metro area. Overall, the KKI School Programs enroll ~500 students coming from over half of the 24 jurisdictions throughout Maryland and employ ~600 school staff. The School Programs at KKI are located in four separate day school settings, three of which are in Baltimore City. A fourth school is in Montgomery County. KKI Schools operate on an 11-month schedule, with two 2-week breaks in July and August. A large proportion of children have ASD, while most of the remaining children have multiple disabilities. The demographic make-up of the students is approximately 46% White and 48% Black/African American, with approximately 8% identifying as Hispanic.

Rochester, New York. The MCC, located in the city of Rochester, provides schooling and clinical support services to approximately 450 children and young adults with moderate-to-severe IDD, many of whom are medically fragile. The great majority of the students are in the age range of 3-18 (3-5: 25%, 6-10: 33%, 11-14: 28%, 15-17: 21%), with ~30% being female, which is consistent with the national IDD population. Fully 70% of MCC students live in poverty, and 54% are from under-represented minority (URM) backgrounds. MCC students are 60% female, 53% non-Hispanic White, 34% non-Hispanic Black, and 9% Hispanic. The study is also enrolling staff members (teachers, therapists, transport workers, etc.), ~75% of whom are female.

Madison, WI. This study includes two cohorts, each with a different testing strategy. The first cohort, focused on in-home testing, is comprised of school-aged children with medical complexity who are cared for at the University of Wisconsin-Madison Pediatric Complex Care Program and who attended school prior to the COVID-19 pandemic. This clinical program delivers care coordination and medical management to publicly insured CMC. The eligibility criteria for this cohort includes children having ≥3 organ systems affected by chronic disease, ≥3 subspecialists, and ≥10 clinic visits or ≥5 hospital days in the year before program referral. Children are assigned a primary care coordinator and a physician or nurse practitioner. The program currently has ~300 CMC, with a mean age of 6 years (range 0-22), who are 44% female, 66% non-Hispanic White, 16% non-Hispanic Black, 10% Hispanic, and 40% live in rural communities.

The second cohort, focused on in-school testing, is comprised of early school-aged children and staff at the Waisman Early Childhood Program (WECP). Housed within the University of Wisconsin Waisman Center, the WECP is a state-licensed program contracted with the Madison Metropolitan School District to provide year-round preschool in an inclusive setting for children ages 1-6 years. Up to 30% of WECP's students have diagnosed special needs, with individualized educational plans and physical, speech, and occupational therapy embedded in a team-teaching curriculum. The WECP serves children and families from diverse backgrounds in 8 classrooms, and children are 45% female, 72% non-Hispanic White, 10% non-Hispanic Black, and 6% Hispanic. This school is in session year-round weekdays, except for holidays and a summer break in August.

STUDY GOALS AND OBJECTIVES

St. Louis, MO and Baltimore, MD. This study uses saliva-based SARS-CoV-2 tests to conduct weekly screening tests of staff and their students with IDD, regardless of whether the participant has symptoms or was exposed. A first goal of the study is to monitor and determine safety and mitigation strategy effectiveness at preventing elevated transmission rates at schools for children with IDD.

We also seek to determine optimal messaging strategies to maximize SARS-CoV-2 virus testing of children and school staff. The KKI/SSD testing project is applying implementation science strategies in a cluster randomized adaptive trial. The Washington University Health Communication Research Laboratory (HCRL) uses an iterative process of environmental scan and pre-testing initial message concepts to translate well-received concepts into prototype messages. The communication strategies were informed by focus groups with parents/guardians of students at SSD schools to capture stakeholder perceptions. Messages are pre-tested to identify messages that are truthful, interesting, original, informative, clear and easy to understand, emotionally evocative, and memorable; stimulate self-reflection; and are perceived by audiences as personally relevant.[25, 26] Messaging strategies include either (a) a general message that is inexpensive and easy to disseminate or (b) a focused message that addresses specific concerns of the different communities. The primary outcome is participation in testing. Secondary outcomes are assessed through validated surveys to determine acceptability, feasibility, appropriateness, the percentage of students and staff who test positive for SARS-CoV-2, and the number of possible SARS-CoV-2 transmission events per student and/or staff within the school setting. The goal is to identify communication strategies that successfully

resonate across communities and those that need to be tailored to address the local environment and beliefs.

Finally, the study seeks to assess perspectives regarding the impact of COVID-19 and the importance of SARS-CoV-2 testing and vaccines among parents of students with disabilities who do not return to in-person instruction. This is being accomplished through fuzzy cognitive mapping, a reliable knowledge-based model that facilitates democratic discourse to understand how stakeholders make decisions,[27, 28] and a national parent survey.

Rochester, New York. This study aims to develop a systems-simulation, model-based virological and serological testing approach that is designed to optimize tracing and isolation processes in an IDD school setting, with the ultimate goal being the ability to preempt disease outbreaks and ensure maximal in-person school participation. Longitudinal and regular virological testing will track infection rates, and serological testing will quantify the durability of protective immunological responses, which may be shorter-lived in IDD populations. The study will also deploy an innovative mobile testing unit for optimal testing flexibility. A strategy to address psychological barriers to full engagement with public health policies, including anxiety about COVID-19, and vaccine and testing hesitancy, will also be developed, emphasizing effective support and educational outreach tools and strategies to mitigate these concerns.

The five main goals of the Rochester study are as follows: ***1) Virological Testing:*** To establish a nasal swab testing regimen approved by U.S. Food and Drug Administration to monitor and

identify disease outbreaks in a specialized school setting that serves 450 children with moderate-to-severe IDD and the 500 staff supporting them, a setting at ultra-high risk for COVID-19 disease transmission. The goal of the study is to rapidly identify infections and develop approaches for isolating and contact-tracing to stem virus spread. ***2) Serological Testing:*** Serology will be used to establish background immunity levels in students and staff, be it from infection or vaccination, and will longitudinally follow those children who are antibody-positive to quantify temporal decay of immunoglobulin G (IgG) and neutralizing antibody levels. The goal of the study is to determine whether protective immunity in children with IDD, a population with prevalent immunological dysfunction, wanes at an accelerated rate compared with the population-at-large; by doing so, we will address an important knowledge gap and provide key data to inform public health policy. ***3) Modeling to Optimize Testing:*** Network models and agent-based simulation models will be developed to guide testing strategies and interventions at MCC. Simulations will be conducted interactively and iteratively to assist in the planning and implementation of testing procedures, exploring the dynamic interplay between school operations and personnel interactions, the potential infection risks and disease dynamics (including variant strains), and implementation of control measures (eg quarantine, isolation, contact-tracing, and vaccination rates). ***4) Mobile Unit Testing:*** To provide the most flexibility to the testing team, we have developed a mobile testing unit that can be readily deployed in the field and go rapidly to where the need for symptomatic testing arises, rather than be fixed *in situ* at the school. In the context of developing potential scalable solutions, it is unreasonable to expect that all IDD specialized school settings will have sufficient space to establish in-house testing facilities. It is also the case that students who may be symptomatic on a given school morning will not travel to the school setting, and indeed, this would not be desirable. Rather,

having the flexibility to go to the homes of students and staff or to deploy to other public venues, may provide for greater testing uptake and convenience for parents, children, and staff. ***5) Understanding and Mitigating Testing & Vaccine Anxiety:*** We will conduct focus group interviews at MCC to identify key community concerns, myths, and misconceptions about vaccination, with a goal of developing a multimodal educational campaign that addresses these concerns. Strategies will include a speakers' bureau, group discussions, and "table talk" conversations, combined with innovative visual approaches that communicate complex information in a readily accessible manner (via graphic medicine) and that promote vaccine uptake (via narrative portraits of trusted peers and coworkers who have chosen to be vaccinated).

Finally, we will assess the impact of this program by deploying a validated, electronic patient-reported outcome scale (PROMIS-29) already in widespread use across the University of Rochester Health System to collect longitudinal data from staff, parents/guardians, and children (by proxy reporting) across multiple health domains (including anxiety, depression, sleep disturbance, and social functioning). This scalable approach will reveal the full impact of the interventions and approaches proposed, and is readily compatible with extension to other sites in the RADx-UP network.

Madison, WI. This prospective cohort study evaluates the feasibility of two SARS-CoV-2 testing strategies and their associations with parent perceptions about in-person school attendance: an in-home testing program for CMC and a school-based testing program for children in an early childhood program. In the first 3 months of enrollment, participants receive

twice-weekly screening testing in addition to as needed symptom- or exposure-based testing via the BinaxNOW Rapid Antigen test platform. In the in-home testing cohort, parents are trained to conduct tests on their child and send logged results to the study team each week. In the school-based testing cohort, research team members conduct tests on-site. After 3 months, participants have the option to opt into continued surveillance or switch to symptom- or exposure-based testing. This adaptive design was chosen because no current scientific data inform when it is safe to curtail COVID-19 surveillance or when testing fatigue influences fidelity. At this point in the study, parents are also actively weighing 2021-2022 school safety. This approach will allow investigators to (1) avoid over-testing and test fatigue and (2) explore novel comparisons based on testing status—surveillance vs symptomatic.

The primary study outcome is the feasibility of each testing strategy, with measures, including protocol updates, data collection and testing response rates, symptomatic and surveillance testing rates, and BinaxNOW positive and false-positive rates. Additional data include demographic, health, and social determinants of health, and parent perceptions about testing and school attendance (ie COVID-19 susceptibility/severity and school benefits, barriers, attitudes, and practices). The adaptive design (ie, providing an opportunity to continue surveillance or switch to symptom- or exposure-based testing) also allows for the following three comparative analyses: (1) statistically significant differences in feasibility or perceptions for in-home cohorts compared with school-based cohorts, (2) frequencies of opting in or out of surveillance within cohorts, and (3) whether differences in perceptions are associated with the change from surveillance to symptom testing. The relatively small number of subjects and expected low COVID-19 positivity rates will make sensitivity and specificity determination of tests difficult.

Finally, because in-home SARS-CoV-2 testing for CMC is novel with little known about this strategy, the quantitative feasibility evaluation is complemented with a qualitative method—contextual inquiry, a human-factors engineering method used to observe people (ie. parents) in their natural 'work environment' (ie homes) while they perform tasks (ie SARS-CoV-2 testing). The purpose of contextual inquiry is to understand how parents perform BinaxNOW testing and interpret results, and where they experience challenges. These findings may influence how we train families, monitor their use, and interpret (as well as improve) test reliability. Such information could increase school administrator confidence to support school attendance, knowing that families conduct high-quality tests and interpret them correctly.

Supporting Schools and Students Today

To provide key stakeholders critical information to address the ongoing public health emergency, the investigators involved in these three Return-to-School projects are making extraordinary efforts to disseminate knowledge as soon as it is learned. These efforts include websites containing content and resources to support school safety for children with IDD and CMC (for example, https://www.reset4kids.org) and national surveys to assess the attitudes of parents and teachers as the pandemic evolves. These dynamic resources, created in partnership with school leaders, state agencies, and advocacy groups, will grow and mature as study results are attained.

SUMMARY AND CONCLUSION

These three RADx-UP Return-to-School projects are implementing several SARS-CoV-2 surveillance testing models for high-risk students with IDD and CMC. Through this work, we

hope to identify generalizable and scalable approaches to facilitate safe school operations for children with IDD and CMC during the current and future pandemics.

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