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# A Vaccine Clinic for Individuals With Neurodevelopmental Disabilities

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We describe how a community partnership led to the development of a coronavirus disease 2019 (COVID) vaccine clinic for individuals with neurodevelopmental disabilities (NDD) that focused on provider training, environmental modifications, and individualized care plans (ICP).

Individuals with NDD encounter the health care system more frequently than their neurotypical peers, are more likely to experience medical trauma and physical restraint, and have much higher rates of unmet health care needs.<sup>1-3</sup> Vaccination rates in children with NDD are consistently low.<sup>4</sup> Barriers to care include limited provider training about NDD, sensory sensitivities, time constraints, vaccine hesitancy among caregivers, and inflexible procedural practices.<sup>5,6</sup> Health care providers describe minimal training related to caring for individuals with NDD and very low levels of confidence in their ability to communicate with patients with NDD.<sup>7</sup> However, few health care systems have adopted a patient-centered approach to training providers about NDD that is collaboratively designed with individuals with NDD and caregivers with lived experience.

The UC Davis Medical Investigation of Neurodevelopmental Disorders (MIND) Institute University Center for Excellence in Developmental Disabilities (CEDD) is 1 of 67 federally designated university centers with the mission to collaborate with individuals with NDD and their families to improve quality of life and community involvement. CEDD employees include self-advocates, caregivers of children and adults with NDD who are trained as family navigators (Katharine), program managers, a caregiver of a child with autism who is a certified child life specialist (CCLS) (Erin), psychologists, licensed clinical social workers, and developmental-behavioral pediatricians (DBP) (Dr Akins).

During the height of the pandemic, many caregivers and self-advocates shared concerns to CEDD staff about obtaining COVID vaccination for family members with NDD who had a history of unsuccessful vaccination. These concerns were discussed at subsequent CEDD meetings that involved self-advocates, caregivers, and leaders from local community-based organizations. These individuals shared their frustration that providers rarely inquired about their child's sensory needs, communication preferences, and trauma triggers before procedures and stated that when caregivers tried to communicate what had worked for their child during previous procedures, the information was often disregarded and almost never communicated to other providers involved in their child's care.

Other caregivers relayed concerns that health care personnel often had a limited understanding of NDD, sensory and communication needs were often unmet, and vocal or motor self-stimulatory behaviors were often misinterpreted as aggression or significant dysregulation when those behaviors often indicated anticipatory anxiety during medical procedures. Lastly, caregivers consistently described fear about completing recommended health care procedures as their children got older and restraint became more challenging.

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Dr Ma conceptualized the manuscript and wrote the first draft and subsequent versions of the manuscript; Ms Roseborough, Ms Tuss, Dr Mello, and Ms Owens contributed to the manuscript and critically reviewed revised versions; Dr Stahmer critically reviewed and revised versions of the manuscript; Dr Akins conceptualized the manuscript, and critically reviewed and revised versions of the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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## **PARENT AND CLINIC CODESIGNER KATHARINE HARLAN OWENS' PRIOR EXPERIENCE WITH VACCINATIONS**

My son was diagnosed with autism spectrum disorder (ASD) and attention deficit hyperactivity disorder in early childhood. Like many other neurodivergent children, he can quickly become dysregulated in medical settings. I remember taking him to a walk-in flu vaccination clinic a few years ago and getting him in the door was a challenge as the space was sterile and uninviting. He is very needle phobic, so when the nurse entered the examination room holding a syringe in her hand, he jumped off the table and ran straight into a glass door. We left the office that day with a bloody lip and without the flu vaccine. I felt terribly guilty as a mother and would never wish that feeling on another parent. I did not know how to fix this situation because no one had ever asked me the right questions to support and prepare my son for vaccinations. I learned over time through education and my experience advocating for his needs that there was a better way to support families. When our parent groups raised concerns about vaccinating neurodivergent children for COVID, I knew I wanted to be part of a project that developed ICP with families during the intake process. I knew that asking the right questions and guiding parents would help get the appropriate supports in place for their children.

## **PARTNERING WITH INDIVIDUALS WITH NDD AND CAREGIVERS TO DEVELOP A PATIENT CENTERED VACCINE CLINIC**

Katharine's experience resembled experiences shared by other families at a subsequent CEDD meeting and staff agreed that a patient-centered vaccination clinic should be designed to meet the needs of individuals with NDD. Caregivers and self-advocates also expressed a belief that when patients with NDD had positive health care experiences, they would often build confidence and trust that could lead to more positive health care experiences.

Caregivers, self-advocates, CCLS, a board-certified behavioral analyst, and DBP subsequently developed a patient-centered vaccine clinic that met the core criteria advanced by self-advocates and caregivers at initial meetings: (1) decrease medical trauma and help individuals with NDD learn to participate in vaccination, (2) train vaccination team members about neurodiversity, comfort positions, visual supports, social narratives, and 1 voice communication, (3) complete intake history and develop ICP before a scheduled vaccination appointment, (4) Avoid using restraints, decrease waiting, and provide visual and sensory supports and longer appointments. The team created a core working group that involved a family navigator and CCLS with lived experience as caregivers of children with ASD, another CCLS with experience in NDD, nurses, pharmacists, and DBP. The core group used Experienced Based Codesign methodology that included longitudinal involvement of patients and caregivers in the clinic design.

The proposed vaccine clinic design was then shared at a follow-up CEDD meeting and staff offered further refinements (ie, dedicated parking, separate entrance, no stethoscopes or laboratory coats, calm postvaccination waiting room, incentives). CCLS worked with caregivers and family navigators to develop training plans, visual supports, social narratives, and structured intake forms. The refined model was then presented to the CEDD Community Advisory Committee (CAC). The CAC includes multiple self-advocates with NDD, caregiver advocates, and professionals representing governmental and non-governmental agencies that serve individuals with disabilities. The CAC was asked to help develop specific aims that addressed health care equity by providing inclusive care for individuals with NDD. They presented the proposed model, then provided open-ended feedback to structured prompts about clinic design in breakout groups, then shared recommendations to full group sessions. CAC feedback was integrated into the final clinic design.

CEDD leaders then presented the proposed model to hospital leadership, who agreed to provide dedicated parking, clinical space, nursing support, and time for training vaccine team staff. Nurses participated in training developed by CCLS that included an overview of neurodiversity, coping assessments, flexible care plans, adaptive supports, sensory needs, comfort positions, and safety skills.

## **ERIN ROSEBOROUGH'S PERSPECTIVE AS A CCLS**

As a CCLS with over 20 years' experience with individuals with NDD, my priority is to formulate ICP to ensure minimal stress and successful experiences during procedures for each patient. A positive health care experience can lead to additional positive experiences that can increase confidence and improve trust in health care overall. This starts with utilizing a structured intake interview several days before any procedure to create an ICP, then sharing the ICP with the procedure team, adapting the environment accordingly, and providing tools that families can use to prepare.

We allow additional time at initial appointments, as some individuals may need to warm-up and wander around tactilely, exploring the space and looking around the room before vaccines are given. This approach also allows staff to use strategies to develop trust, understand communication styles, and build positive interactions with a patient and caregiver before the procedure.

It is also important to inform patients about the procedure and be honest that it may be painful as this is an important part of building trust and self-confidence in one's ability to tolerate some discomfort to remain safe and healthy. Lastly, we recognize that autonomy plays an important role in the experience and offer the opportunity to make choices whenever possible.

## IMPLEMENTING THE VACCINE CLINIC

The clinic was open to all individuals with NDD without insurance restrictions. During the initial intake process, families were asked if the patient had a neurodevelopmental disability. Although we did not require documentation of a diagnosis, nearly all participants had diagnoses of ASD and/or global developmental delay or intellectual disability. Information about the clinic was disseminated through local media, social media, and to local school districts, health care providers, and agencies serving individuals with NDD.

Patients called to schedule appointments, then were contacted by CCLS or a family navigator by telephone 1 to 3 days before their scheduled appointment to complete a structured intake that reviewed each patient's developmental needs, communication style, stressors, successful coping strategies, and preferred items, like favorite toys or foods. This also allowed caregivers to learn about clinic procedures before the visit. Caregivers received educational materials about the vaccination and a social narrative that provided a visual description of each step of the vaccination process. Families were coached on how to use these tools to prepare for the visit.

On the day of the clinic, team members attended a preclinic huddle to review all ICP. Specific environmental adaptations were made based on information shared during the intake. CCLS developed ICP for each patient and as the team developed expertise, a family navigator often partnered with a CCLS to provide supports. Caregiver roles were collaboratively determined before the visit but were adjusted during the visit based on evolving preferences and assessed responses. Patients parked in dedicated spaces near the entrance, entered through a dedicated entrance, were immediately checked in, and directed to a quiet waiting space with preferred supports identified during the clinical intake. Vaccinations were given in a dedicated treatment room. Afterward, patients received rewards and then transitioned to a space designed for comfort and coping for the post vaccination observation period.

## KATHARINE HARLAN OWENS PERSPECTIVE ON PROMOTING ACCESSIBILITY TO HEALTH CARE VACCINE CLINIC AS A PARENT OF A NEURODIVERGENT CHILD

When my son participated in the vaccine clinic, I prepared him using the social narrative and he was able to walk straight into the clinic, but when it came time for the vaccine, he hid behind a table crying. With the help of CCLS, I supported him in my lap as he focused on the Vecta Sensory Machine. Since we had previously discussed his fear of needles, the nurse made sure he never saw the needle and he did great. By the booster dose, he was able to sit alone in the chair and did not shed a single tear! Our experience shows the power that 1 positive vaccination experience can have in building future positive experiences. He is now able to tolerate vaccinations in his pediatrician's office and even in busy, loud pharmacies.

## HOW THIS PARTNERSHIP CHANGED THE PERSPECTIVE OF DRs AKINS AND MA

This initiative taught us the value of creating long term partnerships that are truly patient and family led and rooted in the expertise of those with lived experience. We realized that if we provided basic training about neurodiversity, shared preparatory materials with families, and emphasized partnership, we could facilitate positive health care experiences that minimized medical trauma. Over time, this developmental approach could lead to children with NDD learning to better participate in their own health care.

The success rates were much higher than we anticipated. We realized that positive experiences could start with something as simple as learning a child's favorite things. If a family told us their child liked PAW Patrol and SunChips during the intake, when they arrived, we had PAW Patrol playing on a tablet and SunChips on the table, and they also happened to get a vaccine.

We have seen many children transition to less supported settings and feel the impact of this work most when we receive a message from a family of a child who previously required extensive supports that includes a picture of them proudly flexing their arms to show off their Band-Aid after getting a vaccine in their pediatrician's office.

## TRANSLATING LESSONS LEARNED FROM THE VACCINE CLINIC INTO NEXT STEPS

In the first 2 years, we safely vaccinated 354 individuals with NDD from 3 to 75 years with the COVID vaccine, with a 99.3% success rate (success is defined as having received the vaccine without restraint). In year 3, based on caregiver feedback, we offered both COVID and influenza vaccinations and successfully provided 91 vaccinations, with a 100% success rate.

Although this clinic was developed to address the urgent need to successfully vaccinate individuals with NDD during the pandemic, participants and health care personnel expressed the desire for flexibility and personalized care in all aspects of health care. This led to the development of the Promoting Accessibility to Health care Program, a health system wide initiative focused on improving health care experiences, decreasing medical trauma, and improving the ability of individuals with NDD to participate in their own health care. This work is aligned with a recent consensus statement on Inclusive Healthcare for Youth with NDD.<sup>8</sup>

This vaccine clinic model subsequently informed the redesign of our institution's primary pediatrics phlebotomy clinic. A version of the intake form used in the vaccine clinic has also been incorporated into the electronic medical record via an Epic SmartForm. It is currently being used by pediatric clinics, laboratories, and the Children's Surgery Center, with plans for use throughout the medical system in the near future.

Next steps include developing additional procedure specific toolkits (EEG, radiology) and standardizing trainings by hospital unit or clinic. Training about inclusive care for individuals with NDD is being incorporated into our institution's annual employee and new employee training in 2024.

## CONCLUSIONS

Partnering with caregivers and self-advocates to develop systems of care that result in positive and successful early life medical procedures can increase patient and caregiver confidence, decrease medical trauma, and help patients build the skills they need to successfully participate in medical procedures throughout the lifespan. This developmental approach may be incorporated into training programs that help individuals with NDD and health care providers develop skills needed to decrease the currently unacceptably high degree of medical trauma and unmet health care needs in individuals with NDD.

## ABBREVIATIONS

CAC: Community Advisory Committee

CCLS: certified child life specialists

CEDD: Center for Excellence in Developmental Disabilities

DBP: developmental-behavioral pediatricians

ICP: individualized care plans

MIND: Medical Investigation of Neurodevelopmental Disorders

NDD: neurodevelopmental disabilities

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