Reflections on DC:0-5 at 5

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Abstract
In this article, the authors reflect on the 5 years since the publication of *DC:0-5™: Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* (DC:0–5; ZERO TO THREE, 2016). They describe the context in which the Task Force was created, some of the initial shaping decisions that were made, and the process used to create the revised nosology. The authors highlight the major changes in DC:0–5 and conclude by assessing the value of DC:0–5 based on *a priori* criteria that we established prior to publication.

Early in 2013, ZERO TO THREE created a Task Force to revise *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, Revised Edition* (DC:0–3R, 2005). From the outset, there was a shared consensus that rather than merely an update, this effort would constitute a substantial revision of DC:0–3R. Beyond that, the Diagnostic Classification Revision Task Force was given complete freedom to shape the new version of the nosology.

Context

Early in the 1990s, as the field of infant mental health began to grow worldwide, Stanley Greenspan spearheaded a ZERO TO THREE-sponsored effort to develop a nosology of early childhood mental health and developmental disorders.

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This effort was motivated by the perceived inadequacy of psychiatric nosologies such as *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* (*DSM-IV*; American Psychiatric Association, 1994) and *International Classification of Diseases, 10th edition* (*ICD-10*; World Health Organization, 1992) to describe disorders commonly encountered by practitioners treating young children. The work of the ZERO TO THREE Diagnostic Classification Task Force culminated in the publication of *DC:0–3 Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* (ZERO TO THREE, 1994).

A decade later, in response to burgeoning research on early childhood psychopathology and the publication of the *Research Diagnostic Criteria–Preschool Age* (Task Force on Research Diagnostic Criteria: Infancy and Preschool, 2003), ZERO TO THREE commissioned an update of DC:0–3. Led by Robert Emde, the Revision Task Force spent 2 years reviewing literature, surveying practitioners, and consulting with experts. They produced DC:0–3R (ZERO TO THREE, 2005), a revision of DC:0–3 that updated criteria based on research published

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since 1994 and addressed some of the challenges with DC:0–3 that had become clear in the preceding decade (Egger & Emde, 2011). DC:0–3R, like DC:0–3, was considered a supplement to existing nosologies. No new disorders were added. Disorders that were described in DSM-IV or ICD-10 were not addressed in DC:0–3R, with guidance for practitioners to reference those nosologies.

The rapid advance of knowledge in early childhood mental health led DSM-5 (American Psychiatric Association, 2013) to make some revisions in the criteria for certain disorders to make them more developmentally informed, such as focusing criteria for reactive attachment disorder on attachment behaviors rather than social behaviors more generally and separating disinhibited social engagement disorder from reactive attachment disorder based on research indicating differences in their course, correlates, and responses to treatment. The most significant advance in characterization of early childhood psychopathology, however, was the inclusion in DSM-5 of a preschool subtype of posttraumatic stress disorder. This inclusion was based on careful research indicating that more developmentally sensitive criteria and an alternative algorithm were more valid descriptors of posttraumatic stress disorder in young children than the DSM-IV criteria (Scheeringa et al., 2011). These changes notwithstanding, the DSM-5 contributions to the characterization of psychopathology in young children were relatively modest, and the need for a revision of DC:0–3R remained compelling.

Initial Decisions

In early meetings, the Task Force made framing decisions to guide the process. First, we agreed that all aspects of previous editions of the classification systems would be reviewed and evaluated on their merits rather than being retained because they had been present previously. This review included all disorders, all criteria, and even the multiaxial diagnostic system itself. We determined that all decisions would be informed by extant research and by the considerable clinical experience of Task Force members. We also sought input from practitioners worldwide, including soliciting input from relevant professional organizations such as the World Association for Infant Mental Health (WAIMH), the American Academy of Child and Adolescent Psychiatry, the American Academy of Pediatrics, and the American Psychiatric Association. Finally, to make the process as transparent as possible, we presented regularly at professional meetings, including ZERO TO THREE, WAIMH, American Academy of Child and Adolescent Psychiatry, and we posted preliminary versions of criteria on the ZERO TO THREE website, with requests for comments.

One of the first decisions we made was to extend the age range to cover the first 5 years of life. This extension was unanimously endorsed by the Task Force for the following reasons: the 3–5 year age range also was poorly covered by existing nosologies; many clinical settings serving infants and toddlers also serve preschoolers; and considerable research had been conducted on this age group.

Another decision was that DC:0–5 would be comprehensive and include all relevant disorders for young children rather than refer practitioners to other nosologies such as DSM-5 or ICD-10. We also decided to cluster the disorders into overarching relevant groupings, such as neurodevelopmental disorders; mood disorders; and trauma, stress, and deprivation disorders. We decided to include a diagnostic algorithm with developmentally specified criteria for each disorder to guide practitioners toward more reliable classification. We also committed that, whenever possible and appropriate, we would extend criteria to include infants, including those in the first year of life.

Selected Highlights

Elsewhere, we have highlighted in more detail the major changes in DC:0–5 and the rationale for new disorders (Emde, 2016; Gleason & Humphreys, 2016; Keren, 2016; Soto et al., 2016; Zeanah et al., 2015; Zeanah et al., 2016; Zeanah & Lieberman, 2016; Zeanah et al., 2017a). Here, we call attention to several of the major additions to DC:0–5 compared to its predecessors.

In developing an updated nosology for early childhood disorders, we were aware from the outset of the need to navigate between two concerns. First, some are uncomfortable with the concept of psychopathology in early childhood, especially the use of the term "disorders" in the earliest years of life, preferring instead "risks for psychopathology" or "problems." The concerns derive from a desire not to overpathologize or "label" young children. Rather, the entire effort of the Task Force was driven by our strong belief—supported by voluminous and growing research—indicating that children even in the earliest months of life may suffer and experience impairments from emotional and behavioral disturbances that are neither transient nor trivial (Zeanah et al., 2017b). This leads to the second concern, that we might under-recognize children who are in distress, functionally

impaired, and needing intervention. Of course, many young children experience transient developmental perturbations that are not associated with either impairment or risk for clinical disorders, which led us to be careful about defining disorders. To address concerns about labeling, we emphasized that disorders are diagnosed—not people. To ensure we were not overpathologizing, we included criteria of distress and/or functional impairment as required in each diagnostic algorithm for each disorder. Thus, no young child can meet criteria for a diagnosis without the presence of distress and/or functional impairment, which can reside in the child or family.

Another highlight was that we not only retained the multiaxial classification (see Box 1) to emphasize the importance of context for early childhood psychopathology, but we expanded Axes II through V. Axis II, the relational context axis, includes operationalized criteria for assessing the adaptive qualities both of the young child's primary caregiving relationships and the broader caregiving environment, including co-parenting relationships. Axis III was expanded to include examples of medical disorders that ought to be considered as part of the clinical picture. We expanded and reorganized the psychosocial and environmental stressors in Axis IV. Finally, we reorganized Axis V to focus on developmental competencies, and we included a table detailing developmental milestones.

We added five disorders that had not been included in previous versions of the nosology. Early atypical autism spectrum disorder (EA-ASD), overactivity disorder of toddlerhood, and inhibition to novelty disorder were drawn from empirical demonstrations of continuity between early disturbances in functioning and later disorders. These disorders are explicitly designed to be applicable to infants and/or toddlers only. The fourth new disorder, disorder of dysregulated anger and aggression (DDAA), is a mood disorder intended to capture impairing symptomatic behavior deriving from poorly regulated anger. Many young children with the clinical picture of DDAA would otherwise likely be diagnosed with oppositional defiant disorder, which always included a mixture of mood symptoms and disruptive behaviors. Finally, we introduced relationship specific disorder of infancy/early childhood as an Axis I disorder that defines the relational variability of much psychopathology in young children (see Zeanah & Lieberman, 2016, for a fuller discussion).

To facilitate clinicians' use of the nosology and "crosswalk" DC:0–5 disorders with behavioral health codes recognized by public insurance as eligible conditions, DC:0–5 included sample links between the Axis I disorders and conditions in DSM-5 and ICD-10. In addition, numeric codes were created for each of the Axis I disorders. These inclusions were intended to promote the use of DC:0–5 for eligibility determination, treatment planning, and billing purposes. Also, we hoped that this might encourage use of DC:0–5 in countries outside the US, many of which continue to rely on the ICD nosology.

Box 1. DC:0–5 Axes

Axis I: Clinical Disorders

Axis II: Relational Context

Axis III: Physical Health Conditions and Considerations

Axis IV: Psychosocial Stressors

Axis V: Developmental Competence

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Many young children experience transient developmental perturbations that are not associated with either impairment or risk for clinical disorders.

We were committed to urging deliberate attention to cultural issues in the diagnostic process because of the importance of culture in informing caregiving beliefs and practices, the understanding of infant behavior, and considerations about what constitutes typical and atypical development. We included a cultural formulation for use with infants and young children in the nosology. This formulation, developed by Sarche and colleagues (Sarche et al., 2019), includes attention to the cultural identity of child and caregivers, cultural explanations of the child's presenting problem, cultural factors related to the child's psychosocial and caregiving environment, cultural elements in the relationship between caregivers and practitioners, and an overall cultural assessment for the child's diagnosis and care. DC:0–5 references the importance of cultural context in describing each of the five axes. Axis I includes text and guidance around culture-related diagnostic issues for each clinical disorder.

It is important to note that the introduction to DC:0–5 also clearly defines the scope of a nosology—what it can and cannot do. DC:0–5 offers clearly defined criteria for diagnoses and a multiaxial system that structures comprehensive context information relevant to the diagnostic data. Nevertheless, a nosology cannot serve as an assessment guide nor can it substitute for a practitioner's well thought out formulation.

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Evaluating the Contribution

As we neared completion of DC:0–5, we considered how we would evaluate its acceptability and usefulness. We decided that one obvious indicator of uptake would be sales, given that previous editions had enjoyed widespread use in the US and beyond. Indeed, DC:0–3R was translated from English into nine other languages. A second indicator would be uptake of training opportunities, which ZERO TO THREE determined to make available. Finally, we hoped that having evidence-informed and clearly defined diagnostic criteria would serve as a stimulus to research on early childhood psychopathology.

Sales

As of August 2021, 17,570 copies of DC:0–5 had been sold, including print and digital versions. Also, nine translations had been completed: Chinese, Dutch, French, German, Hebrew, Hungarian, Italian, Portuguese, and Turkish. Another five translations—Japanese, Polish, Russian, South Korean, and Spanish—were underway. These are indicators of meaningful uptake of the nosology by practitioners in many parts of the world.

Training

ZERO TO THREE, in anticipation of national and world-wide use of DC:0–5, wanted to conduct trainings with fidelity to a standard training curriculum. Sherryl Scott Heller from Tulane University was brought on as a consultant to work with Kathy Mulrooney, a member of the Task Force, in creating the DC:0–5 clinical training curriculum and facilitator guide. This curriculum was then reviewed by several of the Task Force members, and a final beta version was completed in 2016. A cadre of DC:0–5 Expert Faculty was selected under a rigorous application and review process 2 months prior to the release of DC:0–5 in December 2016. These faculty represented experienced practitioners/trainers from throughout the US and from Africa, Australia, and Europe. In June 2017, we conducted a DC:0–5 training for trainers, hosted by in New Orleans by Tulane University, Louisiana State University, and the Louisiana Infant Mental Health Association. The original cadre of 14 DC:0–5 Expert Faculty has grown over the years to currently 17 faculty members. ZERO TO THREE recognized the growing need for more local trainers for sustainability of DC:0–5 training. A rigorous certification process of DC:0–5 trainers for state and local training was rolled out with a new "DC:0–5 Training of Trainers" curriculum. At present, there are 44 certified trainers in 17 states in the United States. By August 2021, 102 intensive trainings and 46 overview trainings had been conducted by the DC:0–5 Expert Faculty to a total of 3,000 infant mental health practitioners on five continents, including in Australia, Belgium, Canada, China, Estonia, Hungary, Israel, Italy, Netherlands, South Africa, Sweden, and Switzerland. A "DC:0–5 Faculty Teaching Resource" has been purchased by 103 faculty members across the US and from universities in Australia, Canada, Hungary, Israel, Norway, Poland, Sweden, and Turkey. All of this activity suggests global interest in using a diagnostic classification system for understanding mental health and developmental disorders in young children.

Due to the global SARS-CoV-2 pandemic, ZERO TO THREE in 2020 converted all DC:0–5 trainings to virtual platforms. Doing so required fully revising curricula and activities so that they could be effectively delivered via a videoconference platform. Trainers also strove to maintain participant engagement with the content and with each other and implemented strategies to avoid screen-time fatigue. Both the DC:0–5 Virtual Clinical Training and the DC:0–5 Training of Trainers were successfully implemented on a virtual platform. Responses from these virtual offerings noted that there was a good balance of instruction and interaction and that the dosing of content and pacing was experienced as effective. More details about the ZERO TO THREE DC:0–5 training initiative are available in Williams et al. (this issue, page 30).

Policy and Practice

Acceptance into practice structures through regulatory processes is another measure of uptake.

We are aware that several states have approved use of DC:0–5 for young children covered by Medicaid and that the state of Washington actually requires its use. Inclusion in Medicaid regulations are another indication of acceptance of the nosology. Also, some electronic health records have at least partially integrated DC:0–5 into their systems. Cerner, for example, includes DDAA in its list of diagnoses.

Research

While constructing DC:0–5, the Task Force made use of research in early childhood psychopathology to develop evidence-informed criteria for disorders. This included epidemiological and longitudinal studies that had not been available for previous editions. Still, it was striking how little research seemed to have addressed disorders and other

features of DC:0–3 and DC:0–3R. We hoped that DC:0–5 would inspire more research than its predecessors. To date, however, we have identified limited evidence of relevant research having been published. We are aware of several ongoing data collection projects using DC:0–5, however. Therefore, we consider some of the questions that could be addressed to extend our knowledge base regarding early childhood psychopathology.

Community studies of prevalence and patterns of comorbidity of various disorders defined in DC:0–5 are needed. This research is especially important for new disorders. Also, it is important to delineate the course and predictive validity of some of the new disorders. Early atypical autism spectrum disorder and overactivity disorder of toddlerhood are downward extensions of ASD and attention deficit hyperactivity disorder (ADHD). Given the tendency of neurodevelopmental disorders to persist over time, the question is, how many children diagnosed with these new disorders before they are 2 years old go on to develop ASD and attention deficit hyperactivity disorder? Similarly, inhibition to novelty is another new disorder intended to identify clinically important and functionally impairing behavioral inhibition before a child is 2 years old. The course and predictive validity of this disorder also is important to determine.

Reconceptualized disorders are also important to study. Important questions are how DDAA relates to oppositional defiant disorder and determining the implications of classifying the symptomatic picture as a mood disorder rather than a disruptive behavior disorder, including the subjective experiences of families and providers related to this new conceptualization. Similarly, the DC:0–5 conceptualizations of eating disorders differ from both DSM-5 and DC:0–3R (Keren, 2016). How these different approaches interrelate and respond to treatment will help determine whether broad conceptualizations or more restrictively defined disorders are helpful in determining response to treatment.

The inclusion of relationship specific disorder of infancy/early childhood is a major change from DC:0–3 and DC:0–3R, both of which placed relationship disorders on Axis II. The prevalence, co-morbidity, and especially, response to treatment should be determined. The entire revised Axis II is also an important focus for research and has relevance across multiple disciplines including medicine, developmental and clinical psychology, nursing, counseling, and allied health professions. Understanding how the caregiving relationship affects and is affected by within-child disorders may illuminate which treatments work for whom, a central question in infant mental health.

Conclusions

Five years after publication, DC:0–5 has had demonstrable uptake among practitioners internationally. We believe that use of DC:0–5 on a global scale speaks both to the need for a developmentally appropriate diagnostic classification system and to its clinical usefulness. Sales of digital and print copies of the manual have indicated considerable consumer interest. DC:0–5 is beginning to be more widely addressed in public policy, including public insurance programs (Szekely et.al., 2018). Some states in the US are including specific recommendations for adopting DC:0–5 for clinical practice through the use of crosswalks and recommending or requiring DC:0–5 as the appropriate diagnostic classification system for children under 6 years old. There are efforts to work with Medicaid and other managed health care organizations to reimburse for DC:0–5 clinical diagnoses and to reimburse for more than one diagnostic assessment for infants and young children. More details about how states are integrating DC:0–5 into policy and systems are available in Cohen and Andujar (this issue, p. 40). Various types of training, organized by ZERO TO THREE, have been widely implemented, demand remains high, and feedback has been favorable. Although the Task Force worked hard to create diagnostic algorithms that can be reliably applied in early childhood, research findings addressing key features of the concurrent and predictive validity of DC:0–5 diagnoses or the clinical usefulness of the multiaxial framework for clinical decision making are very limited at the present time. Investment in research capitalizing on advances in the DC:0–5 remains an important indicator to assess going forward.

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Acknowledgments

This work is dedicated to the memory of Robert N. Emde, treasured mentor and colleague. Bob chaired the DC:0–3 Revision Task Force and served as senior advisor to DC:0–5. He was unfailingly supportive and helpful to our efforts. We offer an additional special thanks to Matthew Melmed and to the

Board and staff of ZERO TO THREE for their encouragement and willingness for us to chart our own course throughout our work together.

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Alice S. Carter, PhD, is a professor in the Department of Psychology at the University of Massachusetts Boston. Trained as a clinical psychologist, Dr. Carter's work focuses on young children's development in the context of family relationships, with an emphasis on the early identification of psychopathology and neurodevelopmental disorders as well as factors that place children at risk for difficulties in social and emotional development. She recently completed a large National Institute of Mental Health–funded study designed to address health disparities in age of diagnosis of autism spectrum disorder in partnership with Part C Early Intervention programs in the Greater Boston area that implemented a multistage screening protocol. The multistage screening increased rates of early diagnosis and reduced disparities for Latinx families. Dr. Carter is currently evaluating the effectiveness of a naturalistic developmental behavioral intervention for young children with early signs of autism designed specifically for Part C Early Intervention settings. Dr. Carter was a member of the DC:0–5 Task Force and is currently a DC:0–5 Expert Faculty Member.

Julie Cohen, MSW, is associate director of the ZERO TO THREE Policy Center. During her more than two-decade career at ZERO TO THREE, Ms. Cohen has worked on a wide range of policy issues impacting infants and toddlers, including infant and early childhood mental ealth (IECMH). She is currently a member of the IECMH Policy Team. She was a member of the international expert task force that wrote *DC:0–5™: Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood.* Her portfolio at ZERO TO THREE includes: implementing strategic initiatives and conceptualizing new IECMH projects; overseeing and developing policy briefs, research briefs, articles, guides, memos, blogs, and other resources on IECMH policy; and assisting policymakers and their staff as a technical resource. She is the author of numerous publications.

Helen Egger, MD, is a child psychiatrist and researcher in the developmental epidemiology of early childhood mental health and digital health. With her daughter, Rebecca Egger, she co-founded Little Otter, an early childhood digital mental health company that provides mental health care for children ages birth–14 and their families. After 30+ years in academic medicine, Dr. Egger recently joined Little Otter as chief medical and scientific officer. Prior to joining Little Otter, Dr. Egger was chair of the Department of Child and Adolescent Psychiatry at NYU Langone Health (NYULH), the Arnold Simons Professor, and director of the NYU Langone Child Study Center. She also founded and led the WonderLab, a digital child mental health research lab that created digital products for early childhood mental health research. Before moving to NYU Langone, Dr. Egger was a tenured faculty member at Duke Health where she founded the Early Childhood Mental Health Lab within the Center for Developmental Epidemiology. As the author of the first interview to assess preschool mental health and National Institute of Mental Health–funded longitudinal studies of young children, Dr. Egger has contributed to the science and clinical practice of toddler/preschool mental health. At Duke, Dr. Egger also served as vice-chair and chief of the Division of Child and Adolescent Psychiatry. Dr. Egger was a member of the board of ZERO TO THREE for 13 years and is very proud to have been a member of the ZERO TO THREE Diagnostic Classification: DC:0–3R and DC:0–5 Workgroups.

Mary Margaret Gleason, MD, is a pediatrician and child and adolescent psychiatrist who serves as vice chair of pediatrics at Eastern Virginia Medical School and vice chief of mental health for Children's Hospital of the King's Daughters. She is interested in the clinical care of high-risk young children and their families. In her academic work, Dr. Gleason focuses on early identification of childhood mental health disorder and developing systems of care that bring quality mental health services to young children in mental health settings as well as non-mental health settings. She has developed and validated a screening tool to identify young children at risk for mental health concerns (Early Childhood Screening Assessment) for pediatric practice. She is proud to have served on the Early Brain and Child Development Workgroup of the American Academy of Pediatrics and the Task Force on Integrated Care for the American Academy of Child and Adolescent Psychiatry and to serve on the board of ZERO TO THREE.

Miri Keren, MD, is clinical and research consultant at the Bar Ilan University Affiliated University Hospital in the north of Israel and is in the process of obtaining an academic appointment. She works at the Beit Izi Shapira Center for disabled infants and toddlers, and at the Failure to Thrive unit of the Schneider Hospital for Sick Children. Born in Paris, France, Dr. Keren immigrated to Israel in 1970. She is child and adolescent board-certified and by the School of Psychotherapy at the Tel Aviv University Sackler Medical School where she is currently assistant clinical professor. She is the founder and past director of the community-based infant mental health unit, affiliated to Geha Mental Health Center in Petah-Tiqwa (1996–2020).

She is past president of the World Association of Infant Mental Health (WAIMH; 2012–2016), currently honorary president of the Israel WAIMH Affiliate, and chairperson of the World Psychiatric Association Perinatal and Infant Mental Health Section. She received the Leibovici Award from WAIMH in June 2021. Dr. Keren served on the DC:0–3R Diagnostic Revision Task Force.

Alicia F. Lieberman, PhD, is Irving B. Harris Endowed Chair in Infant Mental Health, professor and vice chair for faculty development at the University of California San Francisco Department of Psychiatry and Behavioral Sciences, and director of the Child Trauma Research Project at the Zuckerberg San Francisco General Hospital. Her research involves treatment outcome studies with infants, toddlers, and preschoolers exposed to family and community violence and other traumatic events. She is the senior developer of child–parent psychotherapy (CPP), a relationship-based, trauma-informed intervention that has extensive evidence of efficacy in randomized clinical trials and is the principal investigator of two Substance Abuse and Mental Health Services Administration grants—one National Child Traumatic Stress Network grant to disseminate CPP nationally and one Infant-Early Childhood Mental Health grant to develop a workforce for infancy and early childhood mental health in rural areas of Northern California, Michigan, Minnesota, and New Mexico. She is the author of several clinical books and a book for parents, *The Emotional Life of the Toddler*, which has been in print for more than 25 years with a second edition published in 2015. She was a member and president of the board of ZERO TO THREE and was on the DC:0–3R Diagnostic Revision Task Force. Born in Paraguay, she received her professional training in Israel and the United States. This cross-cultural experience informs her commitment to closing the mental health services gap for low-income and culturally under-represented young children and families.

Kathleen Mulrooney, MA, LPC, IMH-E® IV (Clinical), works with ZERO TO THREE as director of infant and early childhood mental health strategy in the Program Division. Ms. Mulrooney holds a master of arts degree in clinical psychology and is a licensed professional counselor in New Jersey. She has an extensive history of clinical, training, administrative, and systems consultation experience, specializing in infant and early childhood mental health. In addition, Ms. Mulrooney has worked to support military and veteran families and has done extensive work in disaster and crisis response counseling and training. She was a member of the DC:0–3R Diagnostic Revision Task Force and lead the development of the DC:0–5 training curricula offered through ZERO TO THREE worldwide.

Cindy Oser, RN, MS, retired from ZERO TO THREE in 2019 and now serves as consultant to the Ohio Infant Toddler Court Team Expansion Project, working with the Cuyahoga County Safe Babies Court Team, Children's Defense Fund Ohio, and Groundwork Ohio. Ms. Oser served on the DC:0–3R Diagnostic Revision Task Force from 2013–2016.

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