



## Innovations in Design and Utilization of Measurement Systems to Promote Children's Cognitive, Affective, and Behavioral Health: Workshop in Brief

### DETAILS

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## Innovations in Design and Utilization of Measurement Systems to Promote Children's Cognitive, Affective, and Behavioral Health—Workshop in Brief

On November 5-6, 2014, the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health held a workshop in Washington, D.C., to address advances and gaps in measurement systems to promote children's mental and behavioral health. The workshop featured presentations on the use of data linkage and integration to inform research and practice; the use of quality measures to facilitate change in health care, classroom, and juvenile justice settings; and tools to measure implementation of evidence-based prevention programs. Workshop presenters and participants discussed examples of innovative design and utilization of measurement systems, new approaches to build on existing data structures, and new data systems that could support the cognitive, affective, and behavioral health and well-being of children.

Many different measurement systems track the health and well-being of children in the United States. These systems are designed, in part, to monitor and provide actionable feedback to improve the delivery of health care, social, and environmental services for children at the local, regional, and national levels. They can provide many kinds of information to guide policies and programs, such as:

- the needs and locations of target communities;
- the characteristics of risk and protective factors;
- gaps in health systems, policies, and practices; and
- needs for the overall delivery and quality of care.

However, many of these mechanisms could be improved through tools, such as data linkage and integration, quality improvement methods, and feedback mechanisms.

Hendricks Brown of Northwestern University, the forum cochair, emphasized in his introductory remarks that the data generated and used in one sector rarely cross over into others. For example, information from health care systems is rarely used in schools, and information from the juvenile justice or social welfare systems is rarely used in health care systems. In addition to this lack of connections among systems, there are significant gaps in measuring factors that have an effect on children's health and well-being. New measurement types and uses could provide innovative and efficient ways to assess, assemble, and integrate data to help policy makers and program administrators. Following up on this introduction, forum cochair William Beardslee of Boston Children's Hospital and Harvard Medical School emphasized that the ability to improve the health of children through effective interventions "depends on the collection of data and the use of information for continuous quality improvement, so this is a crucially important forum."

## SUCCESSFUL USE OF DATA INTEGRATION

The workshop's first four presentations, including the keynote address, featured examples of the successful use of data integration to inform research and policy.

### Maryland: Data on Children's Health and Well-Being

Anne Sheridan, former executive director of the Maryland Governor's Office for Children, explained that the state of Maryland uses two major data structures to measure improvements in children's health and well-being. The first is a results and indicators framework, and the second is a rigorous, data-driven process, "state stat," that sets clear expectations about statewide goals. For example, Sheridan explained that, by convening people from the state, foundations, and schools, Maryland was able to provide free and reduced-price breakfasts to an additional 75,000 children by mounting an outreach program that encouraged schools to participate in the program. Sheridan emphasized several factors that were key to the program's success:

- the ability to engage outside partners;
- the role of the state as the innovator and incubator of successful programs; and
- the need to look at improving outcomes as an investment across different levels of government.

### Medicaid: Expenditures for Children with Disruptive Behavior Disorders

Vetisha McClair, a research analyst at the Centers for Medicare & Medicaid Innovation in the Centers for Medicare & Medicaid Services (CMS), described two in-house projects that used health care claims data and detailed analysis to obtain information about health care expenditures. The first project assessed disease prevalence and expenditures for the treatment of disruptive behavior disorders among beneficiaries of Medicaid and the Children's Health Insurance Program (CHIP). The second studied the use of prescription drugs in children among Medicaid beneficiaries. Preliminary results from the data gathered in these studies indicated a slight increase in the prevalence of and payments to Medicaid beneficiaries for the disorders and an increase in the number of children individuals using prescription drugs. McClair drew the following conclusions from these studies:

- The results could be explained by a number of exogenous factors, including changes in delivery systems and state-level Medicaid/CHIP benefits.
- Further research is needed to address how expenditures for children with disruptive behavior disorders vary by state.
- Medicaid data are a viable source of information about health care for vulnerable populations, such as low-income children.

### Illinois: Use of Multiple Service Systems by Families

Robert Goerge, senior research fellow at Chapin Hall, described the Integrated Database on Child and Family Programs in Illinois. The database was created by Chapin Hall, an organization at the University of Chicago that seeks to have an impact on the well-being of children through better research and analysis. The database combines administrative data from a variety of sources, such as law enforcement and Medicaid programs, to learn more about subgroups of families that are at highest risk of their children experiencing adverse childhood experiences.

Analysis of the data illuminated, among other things, the geographic distribution of multisystem families, as well as reports of child abuse or neglect and intentional injury. On the basis of these findings and many others, Goerge offered his conclusions on the broad issue of data integration:

- The flow of information to those who need it is hindered by barriers that differ among locations and sectors.
- In order to effectively use the increasing amount of administrative data collected by states and cities, the greatest need is to better connect academics and government.
- Incentives are needed for all jurisdictions to use their data to get smarter about what they are doing.

### Data for Patient-Centered Outcomes: Keynote Address

In the workshop's keynote address, Jeff Schiff, director of the Medicaid Medical Directors Network, described three of the network's projects with national significance. The first was on the use of psychotropic medicine among children: its findings led to state policies and programs to decrease the use of those medicines in the foster care population. The second project studied hospital readmissions: examining the high rate of readmissions among children and adolescents. The third involved early elective delivery: the network was able to get other organizations that are involved in the issue—such as the American College of Obstetrics and Gynecology, the Collaborative Improvement and Innovation Network of the Maternal and Child Health Bureau, and the National Center for Health Statistics of the Centers for Disease Control and Prevention—to both improve birth outcomes and demonstrate that quality work could be done as a state-led national project.

From the studies he described, Schiff offered several conclusions:

- Sharing information so that states can compare their results to the national aggregate tends to spur quality improvements at the state level.
- Involving states and local-level governments in re-

search creates ownership of the data and quality improvement in outcomes.

- Measurement and quality improvement occur best when the results are relevant to families and front-line providers.
- State-level quality improvements can be linked to state policies.
- Data and program quality improve together.
- Resources and a resourced infrastructure enable data-driven projects to be undertaken.

Schiff emphasized several criteria for the development of measures, including the importance of involving the people who are getting measured. He also pointed out the importance of data linkage—for example, between Medicaid and vital records data—as an opportunity to improve data. In conclusion, Schiff listed several possible topics for the forum to consider:

- foster care and educational outcomes
- autism treatment and outcomes registry
- the diagnosis and educational outcomes for children with attention deficit hyperactivity disorder
- psychotropic medications and race/ethnicity
- behavioral health screening and mental health services
- social complexity and improved well-being.

## MEASUREMENT SYSTEMS FOR ASSESSING CHANGE ACROSS SCALES

Many data systems that already exist can be used to monitor changes in children's health and well-being. The topic was covered in presentations and small-group discussions on how to improve measurement and integration of data at the individual, community, and state levels.

### Population- and State-Level Measurement

Integration of data is a particularly pressing concern at the state level, noted many participants in one of the small-group discussions. They suggested that an interesting project would be to survey state institutions to determine how they are sharing data, how they are disseminating data, and whether they have developed systems that could be shared across the states.

Robert Orwin, a senior study director in the Behavioral Health Group at Westat, described a national health initiative to counter substance abuse: the results were generally quite impressive over a large scale on a state level. The Strategic Prevention Framework State Incentive Grant is an ongoing program of the Substance Abuse and Mental Health Services Administration. Orwin explained that the program is novel for two reasons:

(1) it requires using population-based information to set state priorities and justify resource allocation to communities, and (2) it measures effectiveness by relying on population-based outcomes. In addition, the program's researchers examined which predictors might explain success in reducing substance abuse. They found that community-level factors, such as whether program grants were used to leverage additional prevention funding, were most predictive of success. The researchers also found that the higher the number of environmental strategies that a community implemented, the higher the reductions in substance abuse outcomes.

The small-group discussions also addressed the opportunity for change as the health care system adopts electronic health records—to use data from these records to improve children's health and well-being. They also discussed the importance of interactions among state-level workers and the frontline staff who are often collecting data at the local level.

Kareemah Abdullah, director of the National Community Anti-Drug Coalition Institute and vice president of training operations at Community Anti-Drug Coalitions of America (CADCA), shared a perspective on measurement systems that assess population-level change through coalitions. CADCA supports data-driven strategic planning and prevention of illicit drug use, underage drinking, and youth tobacco use for coalitions across the United States and its territories.

Abdullah described two independent evaluations of CADCA's National Coalition Institute, which provides high-level training and technical assistance for coalitions funded under the Drug-Free Communities Support Act. The evaluation of CADCA's problem-solving approach demonstrated strong effects on population outcomes, such as youth behavior and substance abuse. Abdullah recommended three components for measurement systems for assessing the effect of coalitions on youth behavioral outcomes:

1. They should be simple, with a linear logic model.
2. They should be able to capture varied interactions and outcomes.
3. They should look at complexity-based theories for both action and change.

In small-group discussions, workshop participants also pointed out that it is very important for frontline staff to understand the purpose of the data being collected and to receive technical assistance from the states. Some participants said that community and other local staff need to receive information from the state to maintain and extend their data collection efforts.

Catherine Bradshaw, professor and associate dean for research and faculty development at the University of Virginia's Curry School of Education, presented a glimpse of how people are using datasets in real-world school settings. She described two federal, data-based initiatives in education: the Maryland Safe and Supportive Schools

project and Race to the Top. She then highlighted several common themes from the initiatives:

- The focus and framing of the data dashboard varies by user need.
- Predictive modeling can be helpful for guiding decision making.
- Incentives for data collection and use are important.
- It is important to provide training and a framework for using the collected data and to support decision making.

### Community-Level Measurement

A major issue discussed by the small group on issues at the community level was that a great deal of data is already being collected. However, participants noted that this great wealth of data is highly fragmented, which may result in an inability to form a holistic view of children's health and well-being. The participants said that greater integration, dissemination, and use of these disparate data sources could potentially help achieve many of the objectives sought by workshop participants while reducing duplicated effort. However, noted other participants, greater integration of data will require attention to privacy issues. Participants also noted that although considerable work is being done on the development of new and better assessment tools at the community level, some forms of data, such as various forms of contextual and environmental data, are notably still lacking.

Greg Farber, director of the Office of Technology Development and Coordination at the National Institute of Mental Health (NIMH), discussed one activity of the NIMH data archives, an innovative infrastructure that collects information about research on human subjects and demonstrates the potential of data integration. The infrastructure, which began with the National Database for Autism Research (NDAR) has recently expanded to include all data from clinical trials supported by NIMH and data related to one of its research initiatives. NDAR has developed a "deep federation" in linking with other data repositories ranging from the Autism Tissue Program to the Simons Foundation Autism Research Initiative. The database has "made autism data useful and accessible," said Farber, as demonstrated by the number of users granted access to NDAR and the number of papers being published that are based on data from the registry.

Farber discussed the ways in which NDAR has helped make shared datasets easily accessible to investigators in different fields, describing two principal building blocks that shape how the data are organized. The first is data dictionaries, which define the language characterizing research on autism and other illnesses and provide the

extra benefit of researcher-data quality control. The second is the global unique identifier, which allows data from multiple research projects to be aggregated on the same research participants without having to share personally identifiable information about them.

The small group that discussed NDAR pointed out that the community represents people with a shared interest in the subject, and this kind of focused interest in children may be the foundation for trust and collaboration in building community-oriented data systems.

### Individual-Level Measurement

Jane Pearson, associate director for preventive interventions in NIMH's Division of Services and Intervention Research and chair of the NIMH Suicide Research Consortium, described a prioritized research agenda for suicide prevention that has led to actionable ideas on how to reach individual youth at risk for suicide. By investigating data currently available on youth suicides, two promising places for intervention were identified: emergency rooms and the justice system. In addition, NIMH's work highlighted the importance of measuring the help-seeking behavior of suicidal youths and getting them to the right kind of assistance. "That assistance has included recent efforts to explore the role of social media in relation to youth mental health issues," she said.

The small-group discussion of individual-level measures identified several factors that are currently not being measured, including certain family features, such as family structure, and individual-level markers of biological susceptibility to adversity. Participants pointed out that, in the measurement of services and processes, a team approach could fill existing gaps, especially with colocation and coordination of care. The group also discussed obstacles to data integration, such as developmental changes and the effect of differing cultures and languages across professions.

Data sharing, the group emphasized, requires infrastructure, time, energy, and a willingness to overcome a natural reluctance to share potentially sensitive information. Moreover, no mechanism exists to finance such sharing. Families need to feel they own and trust measurement processes in order to participate fully. Finally, the breakout group discussed the need for public-use measures: common measures that are usable across research, policy, and practice could increase the scope, influence, and power of those measures.



## MEASURES TO FACILITATE SYSTEM CHANGE

In this session, four speakers explained the changes that can occur as the result of the development and implementation of new measures. Two of the speakers used examples, one from child care and one from the juvenile justice system; the other two speakers looked at the overall health care system. They all offered lessons on how to optimize the effects of such changes.

### Child Care and Preschool

Rachel Gordon, professor in the Department of Sociology and associate director of the Institute of Government and Public Affairs at the University of Illinois at Chicago, discussed the recent attention directed by initiatives in child care and preschool to the use of measures that are valid and reliable. She observed that developers and users of measures need to consider both the intent of each research question and its policy use and weigh the evidence for reliability and validity that is appropriate for each case.

Gordon discussed two examples of measurement systems: the Early Childhood Environment Rating Scale (ECERS)<sup>1</sup> and the Classroom Assessment Scoring System (CLASS),<sup>2</sup> both intensive observational measures in classrooms that are used in almost all the states. Gordon notes that while widely used, these measurement systems are limited for high-stakes uses—such as policy decision making, accountability, and quality rating—because they were originally designed to serve different purposes and reflect different developmental approaches. Furthermore, while earlier interpretations concluded strong associations between quality measures and student readiness, she explained that the emerging consensus is that the associations between these measures and student readiness are not always significant and generally have small effect sizes. Additional problems with these measures include low interrater reliability and insufficient control for certain confounding variables. Gordon concluded that information about reliability and validity needs to be independently collected, and she pointed out the potential usefulness of technology to gather evidence and provide feedback for teachers and parents.

### The Juvenile Justice System

Kristen Kracke, a social science specialist at the U.S. Department of Justice's Office of Juvenile Justice and Delinquency Prevention, described the Juvenile Justice Reform and Reinvestment Initiative, a comprehensive approach to reforming the juvenile justice system using a research-based, data-driven, decision-making platform to inform improvements and service delivery. The evidence-based operating platform uses the initiative-developed Standardized Program Evaluation Protocol, which is a holistic process designed to align all parts of the system.

<sup>1</sup>Additional information on ECERS can be found at <http://ers.fpg.unc.edu/early-childhoodenvironment-rating-scale-ecers-r> [March 2015].

<sup>2</sup>Additional information on CLASS can be found at <http://teachstone.com/the-class-system> [March 2015].

The overall system includes the dispositional matrix, a decision-making tool for courts. The underlying principle of the matrix is to place youth in an optimal placement for the youth's needs in the most cost-effective way. Kracke said that the use of the matrix provides "really powerful data" that can be used to monitor the results of differential placement by jurisdictions while not taking away judicial discretion. Kracke concluded by describing the work done by the initiative as "one of the next best things" in helping the "juvenile justice system be rare, fair, and beneficial."

### The Health Care System

Harold Pincus, professor and vice chair of the Department of Psychiatry and codirector of the Irving Institute for Clinical and Translational Research at Columbia University and director of quality and outcomes research at New York-Presbyterian Hospital, discussed some of the recent efforts to build an infrastructure of structural measures with associated process and outcome measures in the health care system. He pointed out some of the obstacles to quality in the health care system, such as a weak measurement and improvement infrastructure, citing many reports of the Institute of Medicine.

Pincus called attention to several key features of quality measurement systems in CMS and the National Quality Strategy established by the Affordable Care Act:

- Measurements can be used to improve performance.
- Indicators can be used to improve quality at the clinical level, the organizational level, and the policy level.
- Measurements can be used for accountability.
- Measures can be used across the different silos of the health care system and at multiple levels.

Pincus concluded by emphasizing the importance of building measurement into the processes of care and the question of accountability.

Sarah Scholle, vice president of research and analysis for the National Committee for Quality Assurance, an independent nonprofit organization, noted that having a quality measure does not necessarily focus attention on improvement. A good-quality measure needs a good evidence base, she said, and draft measure specifications need to be tested with feedback from the people who are going to be measured and the people who are going to use the measure.

Scholle described the work that has been done to improve a measure for adolescent depression, which follows a model in which the responsibility often belongs to the system as a whole, not just to the clinician or the patient. "The logic model for quality measurement starts with structure," said Scholle. She suggested that new efforts to develop quality measures should focus on demonstrating how measures can inform clinical care and provide opportunities to monitor meaningful aspects of quality.

## EFFICIENT AND SUSTAINABLE INTERVENTIONS

Given the need for sustained program quality to improve outcomes, four speakers discussed lessons learned from implementation monitoring.

Richard Catalano, a professor and cofounder of the Social Development Research Group in the School of Social Work at the University of Washington, shared lessons learned from the Communities That Care (CTC) Program. CTC is a proven method to build community commitment and capacity to prevent underage drinking, tobacco use, and delinquent behavior, including violence. Catalano explained that CTC has succeeded by building a prevention infrastructure and creating citizen coalitions of diverse stakeholders who assess and prioritize problems and address them with local prevention programs that are matched to those priorities. Based on CTC's success in getting communities to choose the right programs and achieve positive outcomes, Catalano recommended several actions:

- Build capacity and provide tools for an effective prevention infrastructure.
- Build capacity and provide tools to assess and prioritize local risks, available protective factors, and youth outcomes; match priorities to evidence-based programs; and repeat assessment periodically.
- Build capacity and provide tools to ensure program fidelity and engagement of the target population.
- Create citizen-advocate-scientists to consider and address risk, protection, substance use, delinquency, and violence on a communitywide basis.

Another part of CTC's success, Catalano explained, was the fidelity with which community programs were adopted. CTC's program-selection process presented the need to evaluate fidelity across a range of programs. CTC also developed assessment checklists completed by program staff, coalition members, and reviewed both locally and at the University of Washington.

Lisa Saldana, senior research scientist at Oregon Social Learning Center, noted that there is a growing body of measures that target key aspects of implementation; however, there remains a gap in the measurement of the implementation process itself. Saldana presented the tool, stages of implementation completion (SIC), developed as part of an implementation trial focused on the scale-up of the Multidimensional Treatment Foster Care Intervention. The data-driven tool was developed to measure eight stages of implementation, yielding scores on the amount of time that it takes to complete a stage, the number of recommended activities that were completed, and overall progress along the implementation process.

Saldana acknowledged that the recursive nature of implementation makes it impossible to look at each stage across the entire SIC, but she explained that using Rasch-

based modeling has helped accounted for these difficulties. Analysis of the results has demonstrated the tool's predictive validity in multiple sites, successfully clustering sites by success or failure. Saldana concluded that SIC can provide meaningful prediction of implementation milestones, and results from the SIC can provide data-driven evidence for high-level systems leaders.

Marion Forgatch, senior scientist emerita at the Oregon Social Learning Center and executive director of Implementation Sciences International Inc., discussed another instrument to evaluate implementation fidelity, the Fidelity of Implementation (FIMP), used for assessment of the Parent Management Training Oregon model that provides interventions to parents to help protect and advance the development of children. Technology is a central feature of FIMP evaluation, using a database and Web portal known as FIMP Central. Forgatch cited a recent study showing that fidelity assessment during a program predicts the mechanism for change in the model, validating the predictive power of FIMP as a fidelity measure.

"FIMP also can be measured using computational methods," said Carlos Gallo, a research assistant professor in the Department of Psychiatry and Behavioral Sciences at Northwestern University. He described two examples: a linguistic computational analysis of Familias Unidas, an evidence-based parent training intervention for Hispanic youth, and an analysis of audio clips in the Good Behavior Game, a universal classroom behavior management strategy for first-grade teachers. In Familias Unidas, the computational analysis is used to assess fidelity by examining linguistic aspects of statements and questions that facilitator use with parents. The computational analysis tested in the Good Behavior Game uses recorded audio clips to determine whether teacher statements were made in the required neutral rather than emotional tone. Gallo noted the reliability and success of both measures, noting several advantages of computational linguistics over human raters, such as lower cost.

## PLANNING COMMITTEE FOR THE WORKSHOP ON INNOVATIONS IN DESIGN AND UTILIZATION OF MEASUREMENT SYSTEMS TO PROMOTE CHILDREN'S COGNITIVE, AFFECTIVE, AND BEHAVIORAL HEALTH

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**DISCLAIMER:** This Workshop in Brief has been prepared by **Anita Liu**, rapporteur, as a factual summary of the presentations and discussion at the workshop. The statements made are those of the individual speakers and do not necessarily represent the views of all participants, the planning committee, the National Academies of Sciences, Engineering, and Medicine. The planning committee was responsible only for organizing the workshop, identifying the topics, and choosing speakers.

**REVIEWERS:** To ensure that it meets institutional standards for quality and objectivity, this Workshop in Brief was reviewed by Kimberly E. Hoagwood, Department of Child and Adolescent Psychiatry, New York University School of Medicine, and Vetcha L McClair, Research & Rapid Cycle Evaluation Group, Center for Medicare & Medicaid Innovation, Centers for Medicare & Medicaid Services. Patricia L. Morison, Division of Behavioral and Social Sciences and Education, served as review coordinator. The review comments and draft manuscript remain confidential to protect the integrity of the process.

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## FORUM ON PROMOTING CHILDREN'S COGNITIVE, AFFECTIVE, AND BEHAVIORAL HEALTH

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