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Innovations

FPG Fellow Barbara H. Wasik Serves as Acting Director



hile Samuel L. Odom has been on research leave during the Spring 2015 semester, FPG fellow Barbara H. Wasik has stepped in to serve as acting director. Her scholarship and service on FPG's behalf already have proven invaluable for decades—almost since the Institute's earliest days when its home was a collection of trailers. Among her many projects, she worked with pioneers from FPG's seminal Abecedarian Project in the 1970s on an experimental study of daycare and home visiting, and today, this William R. Kenan, Jr. Distinguished Professor's work continues to advance the field.

Wasik bases her scholarship on an ecological framework, which recognizes how environmental factors interact with personal characteristics to influence behavior, and she has become a national leader in developing interventions for children who are at risk of school failure. Her interventions address a wide range of concerns, including children's social and emotional development, as well as language and literacy development. Within all her work, she has focused on assessment concerns, leading to the development of a number of instruments. She was one of the first researchers to study children's behavior in classrooms, using systematic observational procedures.

During FPG's Carolina Approach to Responsive Education (Project CARE) from 1977 to 1982, Wasik partnered with FPG researchers Craig Ramey, Joseph Sparling, and Donna Bryant. She developed a home-based intervention to help parents learn coping and problem solving skills, an intervention that became the basis for her interest in home visiting. Her early experiences led her to recognize that home visitors received little preparation for their work with families, and she became committed to addressing this gap.

"The lead home visitor in Project CARE was Carrie Bynum, a social worker by training," Wasik said, "but most of the individuals who were providing home visiting in Project CARE had not received training for this role." As a result, efforts shifted to helping the visitors develop the skills necessary for effective home visiting. This work, taking place in the late 1970s, was one of the first efforts in the country to recognize the importance of training and supervision for home visitors.

With other FPG investigators, she also developed the home visiting component of a national experimental study, the Infant Health and Development Program, conducted in eight sites around the country in the 1980s. Her experience with Project CARE and other research have pointed to key elements in supporting effective home visiting.

"Targeting the supervisors of home visitors with information and professional development helps them to understand the importance of training home visitors, monitoring implementation, and having hiring guidelines in place that bring in people who are best-suited for the role," she said.

Despite its many challenges, Wasik explained that the home visiting model also offers advantages. Home visits have the potential to be more family-centered and culturally responsive than other services. They also reduce barriers, such as child care and transportation.

"It is a service that reaches out to individuals in their own homes; it lets families know they are valued," Wasik said.

Wasik's research and service have included consulting for several national organizations, serving on national boards, and holding office in state and national organizations. For the American Psychological Association, she was chair of the Board of Educational Affairs, a member of the Council of Representatives, and chair of the Task Force on Early Childhood Education. She has been president of the North Carolina Psychology Association and an invited participant at the White House Conference on Child Care. She also served on the Committee on Early Childhood Pedagogy of the National Academy of Sciences and was a co-director for the National Forum on Home Visiting.

Although the scope of her expertise reaches well beyond home visiting, that particular subject is especially hot. Fourteen years after the second edition of *Home Visiting: Procedures for Helping Families*, co-authored with Donna Bryant, the book remains the leading reference in the field. She also has plans for a new book: *Home Visiting for the Twenty-First Century*

Wasik's current work also includes development of an online clearinghouse for information and resources on home visiting—complete with a history of home visiting—as well as publishing updated resources for home visitors. All of which means that long after she gives the director's chair back to Odom, Wasik will continue on FPG's behalf to conduct scholarship and service that shape the field.

FPG. Advancing knowledge. Enhancing lives.

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A front-row seat as new medical science unfolds, a new framework for building comprehensive systems, and a new instrument that points to better classrooms for children with disabilities—in this issue of *Early Developments* we tell the stories behind three fascinating and very different innovations.



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On the cutting edge of clinical medicine, diagnostic genomic sequencing offers the opportunity to better understand and address current illnesses and to peer into the future-and FPG senior scientist Debra Skinner is documenting it as it happens.



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They started with a fundamental goal—to identify what a state system needs to put into place to support evidencebased practices for young children with disabilities and their families—and, after 18 months of development, they have created a comprehensive framework.



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n this issue of Early Developments, we tell the stories behind three fascinating, and very different, innovations.

We open with FPG senior scientist Debra Skinner, who is capturing what she calls "the ethnography of the result." With FPG post-doc Kelly Raspberry, Skinner studies the social and cultural aspects of clinical exome sequencing, a cutting-edge option for medical professionals to diagnose the genetic cause of illnesses and their potential courses of treatment. "There are famous chronicles of the discovery of the double helix or of the making of penicillin," Skinner says. "This is one of those times: I get to chronicle genomic medicine as it's being formed."

In our second story, Christina Kasprzak, co-director of FPG's Early Childhood Technical Assistance Center (ECTA Center), says her team's goal was "to design a tool to help each state fully consider what it means to have a high-quality system." After 18 months of thorough collaboration with dozens of experts, the ECTA Center has succeeded; they have created a comprehensive System Framework designed to support states in building and sustaining high-quality early intervention and preschool special education systems.

Our last feature story looks at a pilot study designed to test the results of a new measure, the Inclusive Classroom Profile (ICP). According to ICP developer Elena Soukakou, the rating scale "is measuring what it was designed to measure in a reliable and accurate way." Part of the ICP's effectiveness is its ability to differentiate between the levels of quality in various types of inclusive classrooms, and the instrument will be the subject of much discussion in two special sessions at the National Early Childhood Inclusion Institute. In addition, ICP training also will remain available through FPG's Professional Development Center (the PDC@FPG).

News rounds out this issue of *Early Developments*. We celebrate TA leader Lynne Kahn's career and impact on the occasion of her retirement. We also welcome new members to FPG's executive leadership board and note new awards and honors for FPG's ongoing contributions and innovations.



Chronicling the Cutting Edge

Ethics and the Promise of New Genomic Medicine



Debra Skinner, FPG Senior Scientist

FPG senior scientist **Debra Skinner** has a front-row seat to study what happens at the intersection of the design and practice of a new science.

On the cutting edge of clinical medicine, diagnostic genomic sequencing offers the opportunity to better understand and address current illnesses and to peer into the future. Here, ethics are racing to keep pace with the availability of a new magnitude of information for people seeking answers about their health. "There are famous chronicles of the discovery of the double helix or of the making of penicillin," Skinner said. "This is one of those times: I get to chronicle genomic medicine as it's being formed."

For three years, Skinner and FPG post-doc Kelly Raspberry have worked on the North Carolina Clinical Genomic Evaluation by Next-Generation Exome Sequencing (NCGENES) project at UNC, which is establishing best practices for the use of genomic technologies in medical practice. They study the social and cultural aspects of clinical exome sequencing, a new option for medical professionals that sequences their patients' DNA in order to diagnose the genetic cause of illnesses and their potential courses of treatment.

Analysis of the whole human exome, which constitutes about 1% of the genome, costs less than analyzing the entire genome while offering most of the same clinically relevant information. Not only can whole exome sequencing provide insight into patients' current conditions, it can even forecast conditions patients may suffer from later.

"The clinical application of genomic knowledge is just beginning," Skinner explained. "When we started the project, this application mostly was being done as research, but in the last three years, it's moved into clinical medicine."

NCGENES brings whole exome sequencing to a wide variety of children and adults, including underrepresented populations. "These are people affected by a disease," said Skinner. Other tests have failed to diagnose the cause of the conditions of the several hundred patients enrolled in the project, each of whom researchers suspect has a genetic disorder. "These are people who've already been through other forms of genetic testing, and NCGENES researchers are trying to discover that rare genetic variant that points to an explanation."

From a single vial of blood, whole exome sequencing can examine tens of thousands of genetic variants and find one that causes a single, particular disease.

"Here at UNC, they're really building genomic medicine," Skinner said. Key scientists with NCGENES include UNC's James P. Evans, Jonathan Berg, Gail Henderson, Karen Weck-Taylor, and Kirk Wilhelmsen. "When the project started, a tremendous amount There are famous chronicles of the discovery of the double helix or of the making of penicillin. This is one of those times: I get to chronicle genomic medicine as it's being formed.

—DEBRA SKINNER

of labor went into developing the sequencing pipeline and determining how to interpret the genetic variants. NCGENES investigators are a central part of the national effort that is producing genomic medicine and standards for it. We're seeing science in action."

Not only is the project evaluating the usefulness and effectiveness of whole exome sequencing—and diagnosing many previously un-diagnosable patients along the way—NCGENES is documenting the effects on patients who sometimes learn new and potentially life-altering information in addition to their diagnostic result.

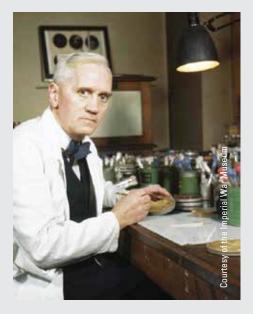
This is where Skinner's expertise comes into play. As a sociocultural and medical anthropologist, she captures what she calls "the ethnography of the result." She and Raspberry catalog the social and technical factors that go into the making of a genomic result, following that result as researchers interpret it and clinicians communicate it to patients—and documenting its impact on patients' lives.

Skinner, director of FPG's Qualitative and Ethnographic Analysis Core, has taken on many seminal roles on projects that have helped young children and their families—including earlier projects that looked at the implications of genetic disease for families and their children. On the NCGENES project, she has been privy to insider discussions from the start as researchers worked to devise standards and best practices related to clinical exome sequencing.

"There has been a tremendous amount of labor in deciding what genetic variants to report to patients," she said. "Do we report only the pathological variants related to the person's illness? What's our obligation to look for secondary findings variants unrelated to the person's illness but that could cause another disease?"

From the beginning, the project team has been aware of the ethical questions raised by the magnitude of potential information available through sequencing.

"It's a fascinating process that requires so many decisions about what to filter out—what genes to look at closely because of their association with disease, what variants within those genes are potentially pathological," Skinner said. "The variants they find are classified into different categories related to how likely they are to cause disease. Some variants are known to be pathological; some are highly suspected to be; some are known to be benign. For those that are suspected, experts sit down as a group and consult multiple databases to make a final decision. Do we report this back or not?



Sir Alexander Flemin's discovery of penicillin changed medicine--and now, so too is diagnostic genomics.

Does this rise to the level of clinical significance?"

The considerations can become extremely complicated, especially because sequencing generates secondary or incidental findings information that wasn't the object of a diagnostic search. It's one thing for a patient participating in NCGENES to learn the cause of his or her disease, but what happens when exome sequencing turns up five other things for which the patient might be at increased risk or even information that is far worse—a dread disease that they are very likely to suffer from?

"What to do with secondary findings is a huge issue in genomic medicine right now," Skinner said. "What's the obligation of a person in the lab running the test, or a researcher or primary care physician to search for secondary findings that aren't the purpose of what you ordered the test for? Should they look for and report back other conditions that are medically treatable? And many patients want to know other conditions they are at risk for, even if they're not considered treatable through medical means."

And then there are the test results that cannot yet be interpreted—when little or nothing is known about the genetic variants—but which might provide valuable, even lifesaving information at some point in the future. As medical knowledge accrues, what happens when progress means the unknown might become known or the untreatable becomes treatable?

"Our people at UNC have been very instrumental in classifying the information that whole exome sequencing generates," Skinner said. "For the diagnostic information they ask: 'Can this variant explain your disease, or do I reasonably think it can?' They also look for and return other secondary information for conditions that are medically treatable. NCGENES participants are told that if sequencing detects these conditions—for example, a mutation that's 80% likely to cause colon cancer and early death—they will be informed, because screenings can be done that may well prevent the cancer's onset."

But what if a patient does not want to learn of this sort of incidental information? Skinner told the story of a clinician who couldn't understand this very scenario, in which he wouldn't be allowed to inform a patient about an illness he could treat. "You can see some of the ethical dilemmas," she said. "Patient autonomy and choice can clash with clinical ethics-the clinician's sense that I could save this person's life. As for the other secondary information that is not medically treatable, we're doing a lot of work in order to give people informed choices on what types of information they may want, or not."

It's a daunting issue. Do patients really want to find out they will develop Alzheimer's or another severely debilitating disease without a current treatment?

"What if I tell you that you have Lou Gehrigs's disease? That's a condition that you can't do anything about, and it progresses to death," she said. "The researchers at NCGENES realized early that it wasn't a simple question about whether patients want to learn their secondary information. Some do. Some only initially may think they do. That's why the researchers separated the information into categories by severity, and educated the patients about the categories before they let them choose which ones they wanted to know. We were worried about how much harm could come from patients just saying they want to know everything they can, without really having thought about it."

Skinner added that some people may want to know about a looming disease even if it cannot be treated so they can live life differently, or be aware of medical advances as they occur and proactively manage their condition, if possible. "But other people don't want to know, and you have to respect that."

Bioethicists and others joined the discussion when the NCGENES team was developing a plan for sharing with patients the information that sequencing could find. "From the beginning, there was an awareness the project had to really help patients to understand and consider their options," said Skinner.

How is it even possible to contextualize the information available to families? Skinner explained that given the nature of the choices that adult patients in the NCGENES project must consider, the researchers ask them not to decide immediately what categories of non-treatable secondary findings they want to learn about.

"I'm present when the clinicians are outlining the choices for people, in those sessions when they're educating people about the categories," she said. "NCGENES requires the patients to go off and think about it. After the patients consider it all, they actually have to make another call back to request their secondary findings."

She also emphasized that the categories of available information are fluid, which introduces another level of complexity to the process. Some results from whole exome sequencing could well carry a different meaning at a later time.

"Variants for which there is little known today might in the future become known causes of particular diseases, and diseases that aren't medically actionable now might be treatable down the road," she said. "That's why there's a really big push for current sequencing projects to build a general database, one that pools and includes all the available information and evidence, in order to make better informed judgments about the associations between variants and diseases."

While the clinicians face a formidable challenge in communicating complex genomic information to patients, the families tasked with understanding it all obviously do, too. According to Skinner, FPG's long history of studying children with disabilities, including children with genetic disorders, dovetails nicely with her work with families in the NCGENES project. At FPG, Skinner previously has studied parent experiences in a pediatric genetics clinic, and last year she wrapped up work on a project that examined families' responses to newborn screening for Fragile X Syndrome.

"We've had—and continue to have—many projects at FPG that conduct family studies and look at the development of children with disabilities, and my role on NCGENES fits squarely into that tradition," she said. "The parents enrolled in NCGENES have had a lot of experiences with their child's disabilities, but they don't know what the genetic cause is. We want to know what difference getting the diagnostic results from sequencing makes for them. And how do they use that information?"

For Skinner, the families' perspectives also are central to a series of important research questions on the secondary findings. Do people actually request this incidental information? What categories of information do they request? Why do they request it? If they don't, why not?

"We interview people about it," she said. "Are you glad you did it? What have you done with the information? Did you find it useful?"

NCGENES behavioral scientist Christine Rini and her team are analyzing those responses now. Skinner said people have requested incidental findings for which there is no medical treatment out of curiosity or a sense of wanting to feel prepared; however, the majority of patients haven't requested the information. "It's also interesting that a lot of people will say they're going to request the information, and then they actually don't. But the project isn't over yet."

Skinner also said that, for several reasons, few, if any, of the study participants have expressed regret at learning their secondary results. Patients receive a negative finding about life-threatening illnesses as good news, even though sequencing cannot detect all such diseases, and positive findings about such illnesses are rare. Some of the other secondary information "isn't particularly useful or earth-shattering." A patient might discover, for instance, that he or she is at a slightly increased risk for diabetes or leprosy.

"Some people are interested in knowing that kind of information, but it's often not relevant on a practical level," Skinner said. "Nor is learning about being a carrier of some disease. Everybody is likely to carry 5-6 recessive conditions, but the other biological parent has to carry the same recessive gene for this to be important, and that's unlikely."

Over her long career at FPG, Skinner has conducted numerous studies on families' understandings of childhood disabilities and on the broader cultural, economic, and political contexts of their beliefs and practices. She has developed theoretical models and methods to assess personal identity and parental beliefs, and her research has included family and poverty studies in urban and rural areas. But the rise of whole exome sequencing means that at this moment she is riding the wave of new medical science as it crests.

Her role as the chronicler both of the day-to-day inner workings at NCGENES and of the reactions of its patients remains central to understanding the ethnography of the result—and to applying what the project learns on a much broader basis. She continues to record the story of how patients, clinicians, and researchers wrestle with ethical issues and medical uncertainty one diagnosis at a time.

"Nobody's got all the answers," she said. "The geneticists will tell you there's still so much we don't know."

Read more about NCGENES med.unc.edu/ncgenes

BUILDING The ECTA Center's HIGHOUALITY New System Framework SYSTENS

hey started with a fundamental goal: to identify what a state system needs to put into place to support evidence-based practices for young children with disabilities and their families. Now, after 18 months of development, they have created a comprehensive tool—the *System Framework*—designed to support states in building and sustaining high-quality early intervention and preschool special education systems.

"Essentially, we wanted to put together the content for states to be able to evaluate their systems and then use that data to plan for improvement," said Christina Kasprzak, director of FPG's Early Childhood Technical Assistance Center (ECTA Center), which spearheaded the development of the framework "We wanted to design a tool to help each state fully consider what it means to have a high-quality system."

Strengthening Capacity of State Data Systems



According to Martha Diefendorf, co-lead of DaSy TA Planning and Coordination, helping to improve services for every child means being able to answer key questions.

"Where do kids do better?" she said. "Which children have better outcomes when they enter preschool? What are the characteristics of effective programs? What are the characteristics of the workforce that predict the best outcomes?" Diefendorf noted that with the right tools and strategies, the answers to these and many other critical questions can arise from the wide array of data compiled by state early intervention (Part C) and preschool special education programs (Section 619) supported through the Individuals with Disabilities Education Act (IDEA).

"States want to improve their data sets," said Diefendorf. "DaSy helps them focus on the quality and depth of their data and on building new linkages with data from other programs."

The Office of Special Education Programs funded the DaSy Center, which is a multiinstitutional collaborative effort to work with state Part C and 619 coordinators and data managers, local administrators, technical assistance specialists, and others. DaSy tailors its support to be responsive to needs of states of different sizes and with different structures, but the end goal always remains the same: helping to arm decision-makers with the right information to improve programs for young children with special needs.

According to Diefendorf, the quality of the data is paramount. "Data collection is an important emphasis," she said. "A primary consideration, of course, is how useful the data will be."

Not surprisingly, the process of building an effective statewide data system—capable of crossing agency boundaries and tracking information over several years—comes with several challenges.

"Sometimes the people who need to use the data are not necessarily the people who construct the system," Diefendorf said. "Administrators also can face constraints due to resources and finances, as well as having to resolve issues about privacy and confidentiality and who governs the data."

She added that some states have systems in place but don't have the tools to tweak or overhaul them—or even to decide which course would be better. DaSy also helps states make better use of the information they already have on hand.

Despite the numerous complexities involved in building a useful data system, Diefendorf said FPG's rich history of technical assistance successes make her optimistic. "Ten years ago, we faced a similar challenge with helping states report on child and family outcomes, but thanks to the Early Childhood Outcomes Center, every state today can report on major outcomes."

Part of Diefendorf's optimism also comes from DaSy's strong partnership with seven states to develop the *DaSy Data System Framework*. As a component of the *ECTA System Framework*, the *Data System Framework* is organized around six subcomponents: Purpose and Vision, Data Governance and Management, Stakeholder Engagement, System Design and Development, Data Use, and Sustainability.

Through numerous quality indicators across several components, the new *DaSy Data System Framework* conveys the characteristics and capabilities of an effective, integrated state data system knowledge that can help decision-makers to lead or actively participate in developing their state's data system.

As a result, new or enhanced data systems will enable states to comply with federal reporting requirements to answer important program and policy questions and inform program improvement.

"In the end, states will be able to build better systems of services and programs," said Diefendorf. "And that can improve outcomes for young children with disabilities and for their families." Katy McCullough, a technical assistance specialist at the ECTA Center, said that from the initial stages of building the *System Framework*, the Center kept its eye on the end game: positive outcomes for children with disabilities and families receiving services under Part C and Section 619 of the Individuals with Disabilities Education Act (IDEA).

"We started by asking: What actually has to be in place for that to happen?" she said. "The answer: implementation of effective practices. Then, how do we ensure that those will be in place? Well, that's where the framework comes in."

According to Kasprzak, early intervention (Part C) and preschool special education (Section 619) state coordinators are the framework's primary audience. Development of the framework included state coordinators from six partner states and dozens of additional experts and authorities, including core staff at the ECTA Center, other crucial personnel in the partner states, and a technical work group of renowned early childhood professionals.

"It was a huge team," said Kasprzak. "We wanted to make sure we heard as many voices as possible to help us come to consensus."

Many states applied to partner with the ECTA Center to develop and test the framework. In the end, Delaware, Idaho, Minnesota, New Jersey, Pennsylvania, and West Virginia met selection criteria shaped in part by the need to include a representative variety of service delivery systems. Kasprzak explained that states vary significantly in their Part C and Section 619 service delivery systems, but thanks to the representative array of service delivery systems in the partner states and the wide range of expertise providing feedback along the way, the System Framework accommodates such variation.

"States have been very interested in seeing the final version of the System



Framework," she said. "And partner states were eager to be part of the process, getting to have a look at versions of the framework before the rest of the field and having a chance to shape it."

Kasprzak said the process started with a review of the literature and current research findings, as well as discussions with partner states about what was working in their states and what could be improved. "We asked our partners if they had particular policies in place," she said. "If their policies were being implemented well, if they were evolving and being revisited, given new knowledge and research."

"It was an iterative process," said McCullough. "Part C and 619 folks were very active. For each component of the system we asked our partner states what they were trying to achieve and what quality meant in their contexts, and along the way we got some nice feedback, validating what we were doing, as well as some really good input that sparked us to revisit draft content."

The ECTA Center and its collaborators organized the System Framework around six interrelated components, each of which is integral to ensuring the implementation of effective practices. The team further developed subcomponents and detailed indicators of quality, in the end providing a multi-layered outline for state Part C and Section 619 programs to address the areas of "governance," "finance," "personnel/ workforce," "accountability and quality improvement," "quality standards," and last but certainly not least, "data system."

"When we began to conceptualize the framework, we landed on several cross-cutting themes," said McCullough. "Using data for improvement was one of the most important. We want to make sure states are getting the data they need to make good decisions." Other important cross-cutting themes include: family leadership and support; coordinating or integrating across the broader early childhood service sector; stakeholder engagement; establishing/ revising policies; promoting collaboration; and communicating effectively.

Kasprzak and McCullough credited the Center for IDEA Early Childhood Data Systems (DaSy) with developing the framework's "data system" component. (See "Strengthening Capacity of State Data Systems.") The ECTA Center also collaborated closely with the Early Childhood Personnel Center to develop the "personnel/workforce" component and with the Early Childhood Systems Working Group, a group of national leaders supporting the efforts of states to build comprehensive early childhood systems.

In partnership with the DaSy Center, the ECTA Center also has developed a corresponding self-assessment for the framework to assist states as they evaluate their Part C and Section 619 systems to identify strengths and weaknesses, develop plans for improvement, implement those plans, and track improvement.

"We hope that rich conversations will happen in states around the framework content," Kasprzak said. "States can use the framework and the self-assessment to identify areas for improvement."

She added that the ECTA Center is compiling a set of resources to accompany the framework and will support states as they use the framework, the self-assessment, and the accompanying resources to improve their service systems—with the ultimate goal of enhancing outcomes for young children with disabilities and their families.

The U.S. Department of Education's Office of Special Education Programs funded the development of the *System Framework*.

The ECTA Center's *System Framework*: http://ectacenter.org/sysframe

More on the ECTA Center ectacenter.org









The Inclusive Classroom Profile

Measuring Instructional Practices in Inclusive Preschool Settings

A pilot study in 51 North Carolina classrooms shows the effectiveness of a new measure in assessing the quality of practices in inclusive preschools. Not only is the *Inclusive Classroom Profile* (ICP) a reliable instrument, researchers say it also reveals the types of inclusive settings that may be best serving preschoolers with disabilities.

"Inclusion encourages active participation and a sense of belonging and membership for all children, with and without disabilities, who learn and develop in the same classroom," explained the study's lead author Elena P. Soukakou, senior lecturer at the University of Roehampton in London and a former post-doc at FPG. "This is an important aim of early childhood education." Soukakou, who developed the ICP as part of her dissertation study at Oxford University, explained that research already exists that can help programs to enhance the quality of their inclusive settings.

"We know that specialized instructional techniques and the use of assistive technology will support the development and learning of young children with disabilities in inclusive settings," Soukakou said. "We also know that a range of factors—such as program standards, professional development, and resources—are likely to affect the quality of inclusive classrooms."

Federal and state laws and policies mandate inclusion for young children with disabilities. However, a 2014 report from the Office of Special Education Programs informed Congress that less than two-thirds of all preschool children with disabilities who were served under the provisions

2015 National Early Childhood Inclusion Institute Presenters and Sessions



FPG's National Early Childhood Inclusion Institute is the premier event for people from all early childhood sectors to come together to learn, share, and problem-solve about inclusion for young children. In addition to FPG investigator Tracey West, who leads two special sessions on the Inclusive Classroom Profile this year, the Inclusion Institute features dozens of other expert presenters across three days packed with programming.

Opening day will feature a formidable and multi-talented mother-daughter team renowned for their service and advocacy. Ann Turnbull, co-founder of the University of Kansas's Beach Center on Disability, and daughter Kate Turnbull, a mindfulness coach who works with children with ADHD, will deliver the keynote address at the popular three-day conference and play key roles in several other Institute offerings.

The special education field has long hailed Ann Turnbull as a leading researcher on family support, family quality of life, familyprofessional partnerships, and other topics but national and international family networks also recognize the Beach Distinguished Professor Emerita as a visionary and relentless advocate and leader. She said she is excited to co-present the keynote address with daughter Kate because of Kate's insights about having grown up with her brother Jay (1967-2009), who had multiple disabilities.





of the Individuals with Disabilities Education Act were enrolled for some amount of time in regular early childhood settings.

"Children with disabilities should have the option of receiving their specialized services in the same settings as their typically developing peers, instead of in isolated classrooms," said co-author Pamela J. Winton, a senior scientist and director of outreach at FPG. "But teachers may feel unsupported and unprepared to serve some children adequately."

Winton explained that in order for inclusion to succeed, administrators, specialists, teachers, and families must actively collaborate to meet the needs of children with disabilities. "And studies show that when we do it right, inclusion benefits all children—those with and without disabilities."

Given the legislative support for inclusion and the research behind it, Winton said it is surprising that little is known about the implementation of quality practices that support the learning and development of young children with disabilities in real-world early childhood settings.

"Especially given the current context, in which improving the quality of early childhood programs serving high needs children has become a national education priority," Winton said. "The Race to the Top–Early Learning Challenge Program and other reform efforts are challenging states to develop systems for rating, monitoring, and improving early learning and development programs to serve each and every child."

Winton said that thanks to the ICP researchers now can capture important information about what's happening on the ground.

Each of the instrument's 12 items elicits ratings of researchbacked practices to see how much a program's staff adapts the Inclusion encourages active participation and a sense of belonging and membership for all children, with and without disabilities, who learn and develop in the same classroom.

—ELENA P. SOUKAKOU

"What happens to siblings becomes part of their being," Ann said. At past Inclusion Institutes, Ann talked about her family's quest to support Jay in having an "enviable life." This is the first time, though, that Kate will share her own journey with Jay at the conference.

During the upcoming keynote, which will focus on launching siblings of children with disabilities to lives full of well-being, Kate plans to make recommendations about how families and practitioners can nurture sibling relationships. Ann will join Kate in providing an overview of what research reveals about sibling impact, support, and roles.

Afterward, Ann and Kate will serve as cofacilitators for a special opening day panel that will continue the discussion on siblings and families. In addition, the Institute will offer a panel of federal early childhood leaders with emerging information on policies and insights about enhancing the quality of inclusive services.

Ann and Kate each will also contribute to one of the dozens of concurrent sessions slated for the conference. Based on Ann's decades of research, advocacy, and leadership of national professional and family organizations, she will offer a session on "Empathetic Communication." Kate, drawing on the importance of mindfulness in her adult life and her experience using it with children, will present "Focusing Attention: Mindfulness Training for Young Children with Self-Regulation Challenges."

This year the conference sold out two months in advance. "I love the people at the Inclusion Institute," Ann said. "I love to participate in it for the relationships."

More about FPG's National Early Childhood Inclusion Institute

inclusioninstitute.fpg.unc.edu

classroom's environment, activities, and instructional support in ways that encourage the active participation of each child with disabilities. Soukakou trained experienced raters who then took the ICP to inclusive preschools serving 2-5 year-olds in 46 counties across North Carolina, where the raters used the measure to observe classrooms in which one or more children had an identified disability.

"The study showed that the ICP rating scale is measuring what it was designed to measure in a reliable and accurate way," Soukakou said, adding that the study found part of the ICP's effectiveness is its ability to differentiate between the levels of quality in various types of inclusive classrooms.

"Head Start and public pre-k settings significantly outscored the licensed child care programs," she said. "Developmental day programs scored highest of all."

In North Carolina, developmental day programs are certified to provide specialized services to children with identified disabilities, include at least one staff member who holds certification or licensure issued from the state's Department of Public Instruction, and meet teacher-child ratio requirements.

Co-author Tracey West, an investigator at FPG, said better quality of inclusive practices at Head Start, public pre-k, and developmental day settings could be a result of child care programs never having had a direct mandate or mission associated with serving children with disabilities.

"Nor have they had systematic technical assistance related to serving children with disabilities, which has been more widely available historically to the other programs," said West, who delivers training on the ICP through FPG's Professional Development Center (PDC@FPG).

West will present the study's findings while leading two special sessions at this year's National Early Childhood Inclusion Institute, and participants will have the opportunity to familiarize themselves with practices that the ICP assesses and hear other important updates. Soukakou said such sessions provide opportunities for participants to explore and discuss how the tool might support their own work.

"The most meaningful purpose of any classroom quality assessment system is to support teaching and practice," Soukakou said. "My hope is that the ICP will not only help people in assessing the quality of implemented inclusive practices, but also in identifying areas for improvement and developing relevant action plans to support the needs of all the diverse learners included in early childhood classrooms."

Training on the *Inclusive Classroom Profile* through the PDC@FPG

pdc.fpg.unc.edu/using-inclusiveclassroom-profile-proficiency

Online modules on the ICP

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Trohanis Technical Assistance Projects' Co-Director Lynne Kahn Retires



While FPG director Samuel L. Odom is on research leave, acting director Barbara H. Wasik compiled the following tribute to mark the retirement of Lynne Kahn, co-director of the Trohanis Technical Assistance Projects (named after TA pioneer Pat Trohanis). For the past three decades, Lynne Kahn has been an integral contributor to TA projects at FPG, including leadership roles with the National Early Childhood Technical Assistance Center (NECTAC), the Early Childhood Technical Assistance Center (the ECTA Center), and other projects.

WW hile Sam Odom is on leave, I have the pleasure of recognizing Dr. Lynne Kahn on the occasion of her retirement at the end of February after a long and illustrious career at FPG. She has been a part of our organization for 30 years, serving children with disabilities and their families at the local, state, and national levels with distinction and dedication.

She is much admired by colleagues both here at FPG and nationally. Some of our FPG colleagues who have worked most closely with Lynne have captured for us what it has meant to work with her.

Betsy Ayankoya, associate director (technical assistance), ECTA Center:

"Lynne has taught us so much about collaboration! She has been a positive influence on our work with other organizations and projects on behalf of all young children. Her idea for 'co-staffing' with national centers stretched us in so many ways and helped us to learn new content and function in different contexts. We'd like to think that we're both stronger and wiser because of her leadership!"

Joan Danaher, associate director (information resources), ECTA Center:

"When Pat Trohanis died in 2007, at the urging of her colleagues, Lynne stepped up to lead NECTAC, to prepare us to compete successfully for the ECTA Center, and to grow the Trohanis TA Projects group at FPG. Lynne possessed the expertise to meet the demands of her new role from her many years of experience in evaluating technical assistance and program outcomes and in designing an approach to TA for state systems improvement. She laid the foundation for our current work in developing and implementing a state system framework; implementing evidence based practices; and, improving data and outcomes for young children with disabilities and their families. Her collaboration with funders and peer TA projects has benefited, and will continue to benefit, the programs we serve directly as well as other early childhood programs that interface with early intervention and early childhood special education. She has been committed to nurturing and mentoring the next generation of TA leaders and leaves us in good stead."

Robin Rooney, principal investigator, North Carolina Early Learning Network:

"I'd like to acknowledge Lynne's critical role in guiding the creation of our statewide training and TA system for preschool in NC: the Early Learning Network. With her help we've gotten the network up and running—on high speed—in less than two years. Could never have accomplished that without her!"

Christina Kasprzak, the newly appointed director of the ECTA:

"Lynne has been a national leader in the field of TA to Part C and Section 619 systems, leading many of the OSEP-funded TA projects at FPG, including NECTAC, the ECTA Center, the Early Childhood Outcomes (ECO) Center, the Center for IDEA Early Childhood Data Systems (DaSy), and the IDEA Data Center (IDC). She is passionate about what it means to provide high quality TA—helping people do whatever it is they're trying to do more efficiently and more effectively. For over 30 years, she has been responding to the needs of early intervention and preschool special education programs in order to help them improve their systems, services, and ultimately the outcomes for young children with disabilities and their families. On a more personal level, I will say that she is incredibly smart and supportive and cares very much about those she works with."

Though Lynne is formally retiring, she is not ending her involvement in all professional activities, but I do wish her time in this next chapter of her life to enjoy other things she has not had time for during the past years. Thank you, Lynne, for your professional contributions both inside and beyond FPG.

Sincerely yours,

Barbara H. Wasik, Acting Director Frank Porter Graham Child Development Institute William R. Kenan Jr. Professor, UNC School of Education

For more on Lynne Kahn and FPG's 40-year commitment to pioneering technical assistance

fpg.unc.edu/news/42-year-tradition-fortifies-fpgs-new-technicalassistance-projects

For the latest on TA at FPG, see this issue's feature on the ECTA Center's new System Framework.

FPG Welcomes New Members to the Executive Leadership Board

PG's Executive Leadership Board welcomes five new members to
its team. These expert advisors offer their knowledge and expertise to help define FPG's mission and focus.

New board members include:

Tamara Barringer, state senator from North Carolina's 17th district and former managing partner of the Barringer Law Firm. She also is a former PTA president and longtime public school volunteer, who believes "We must give our teachers the tools they need to get our students career ready."

Kenneth A. Dodge, the founding director of the Duke Center for Child and Family Policy. Dodge's work bridges basic scientific research in children's development with public policy affecting children and families.

Eugene Garcia, professor emeritus at Arizona State University and former senior officer in the U.S. Department of Education. Garcia has published extensively in the areas of early learning, bilingual development, and equal educational opportunity.

Michael L. Lopez, principle associate in the Education Practice at Abt Associates, who leads the new National Research Center on Hispanic Children and Families. He is a renowned authority on the development, education, and wellbeing of young children, particularly low-income and culturally and linguistically diverse populations.

Liz Pungello, president of the Brady Education Foundation, which promotes collaboration between researchers and educators in order to close the achievement gap for children at risk for poor school outcomes. She is a research associate professor in the Developmental Psychology Program at UNC-Chapel Hill and a former scientist on FPG's Abecedarian Project.

These five new experts join the following members already serving on FPG's Executive Leadership Board:

W. Steven Barnett

Director, National Institute for Early Education Research, Rutgers University

Barbara T. Bowman

Irving B. Harris Professor of Child Development, Erikson Institute

Peggy Carter

Chair, Board of Directors, Winston-Salem State University Foundation

Ron Haskins

Senior Fellow, Economic Studies Co-Director, Center on Children and Families, The Brookings Institution

Olson Huff

Medical Director Emeritus, Mission Children's Hospital

Hal Kaplan

President and CEO, Kaplan Early Learning Company

David Lawrence Jr.

President, Early Childhood Initiative Foundation

Howard Lee

President, Howard N. Lee Institute Formerly, North Carolina State Board of Education

Marvin McKinney UNC/FPG Research Fellow Formerly, W.K. Kellogg Foundation

Evelyn Moore

President Emeritus, National Black Child Development Institute

Duncan Munn

Munn & Munn, LLC Formerly, Division of Early Intervention and Education, NC Department of Health and Human Services

James M. Perrin

Professor of Pediatrics, Harvard Medical School Director, Center for Child and Adolescent Health Policy, Massachusetts General Hospital

Karen Ponder, Owner Ponder Early Childhood, Inc. Formerly, North Carolina Partnership for Children

Donald J. Stedman, President and CEO New Voices Foundation Formerly, Dean of the UNC-CH School of Education



FPG director Samuel L. Odom (left) with executive leadership board member Don Stedman

Under Stedman's leadership, New Voices Foundation has worked with public schools to improve educational opportunities for children with severe communication and mobility disabilities. The foundation supports teachers and future teachers, as well as other professionals, by enhancing their abilities to serve children.

Stedman will remain an active leader on the planning team for FPG's 50th anniversary.

To make a gift to FPG's 50th Anniversary Celebration fpg.unc.edu/support-fpg

Inaugural Gift from New Voices Foundation Launches Plans for FPG's 50th Anniversary

Don Stedman, co-founder of New Voices Foundation, has presented FPG with the first donation designated to celebrate the institute's 50th anniversary in 2016.

"FPG is a world class child development organization," said Stedman, former dean of UNC's School of Education and former associate director of FPG. "A half century of work has helped transform both how and when children need educational support to make their lives better and richer."

Stedman presented the \$5000 gift at the annual meeting of FPG's Executive Leadership Board, on which he has served for several years. Celebratory plans include a two-day symposium in May 2016 to discuss state-of-the-art research and practice, as well as new directions for FPG and the fields of child development and education.

According to Stedman, the event will include opportunities to look at what FPG and its many researchers, past and present, have done to enrich the lives of children.

"But, best of all, it will examine what the futures of children need to be and how research can make that happen," he said. "New Voices Foundation is proud to play even a small part in helping to launch the planning and development of this historic event."

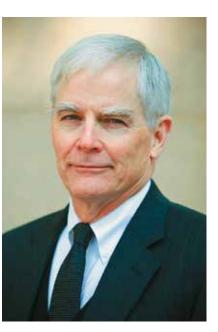
FPG Executive Leadership Board's Ron Haskins Receives Award

UNC's School of Education has honored FPG executive leadership board member Ron Haskins with the Alumni Achievement Award.

Since 2001, Haskins has served as senior fellow and co-director of the Brookings Institution's Center on Children and Families, and Brookings recently named him the Cabot Family Chair in Economic Studies. He also serves on North Carolina's Early Childhood Advisory Council, as well as on the board of the UNC School of Education Foundation.

During his four-decade commitment to children, Haskins made his name as a data-driven scholar, influential policymaker, respected author, and college professor. He earned three degrees from UNC: a bachelor's in history, a master's in teaching, and a doctorate in developmental psychology. From 1973 to 1985 he held several titles at FPG. He later became a Congressional Science Fellow for U.S. Senator Paul Simon, opening a career in Washington that has addressed evidence-based policy, early childhood education, marriage and family formation, poverty, equal opportunity, abused and neglected children, and budget issues.

His lengthy catalog of publications includes three editions of the *Green Book*, a 1,600page compendium of the nation's social programs, published by the House Ways and Means



FPG executive leadership board member Ron Haskins

Committee. He also co-edited *Policies for America's Schools: Teachers, Equity, and Indicators* and co-authored *Show Me the Evidence: Obama's Fight for Rigor and Results in Social Policy,* his most recent book.

Haskins frequently appears on radio and television and has penned articles and editorials for numerous newspapers and other publications, including the Washington Post, New York Times, Wall Street Journal, Policy Review, State Government News, American Enterprise, National Review, and the Weekly Standard.

New Era of Leadership Opens at FPG's National Implementation Research Network

When Dean Fixsen and Karen Blase created the National Implementation Research Network (NIRN) in 2002 to accelerate growth in the field of implementation science, only a handful of implementation experts existed. With FPG's support, NIRN has since flourished, organizing practitioners, program developers, researchers, and policymakers—and people in numerous roles and disciplines have come to better understand the benefits of implementation science. Now, NIRN encounters new opportunities as its co-founders have passed the responsibilities for leading the seminal FPG project to scientists Melissa Van Dyke and Allison J. Metz, two highly respected implementation experts who served as co-directors of NIRN for the previous year with Fixsen and Blase.

The inaugural issue of *Implementation Science* defined their discipline as "the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice," often in typical service and community settings. As a field, the science and practice of implementation has been developing since the Great Society programs began in the 1960s. By the time Fixsen and Blase created NIRN, they already had spent decades learning about evidence-based programs and how to use them with optimal results in many different settings.

"It had become clear that implementation was the key to realizing the benefits of evidence-based programs on a socially significant scale," said Fixsen.

Today, implementation science is hot. In a recent edition of *Exceptional Children*, Fixsen, Blase, Metz, and Van Dyke identified the main reason for its demand: the powerful inertia to which systems naturally succumb and which can "overwhelm virtually any attempt to use new evidence-based programs." Not surprisingly, a passive "train and hope" approach to implementation rarely succeeds in the meaningful realization of evidence-based practices.



Dean Fixsen and Karen Blase, flanked by Melissa Van Dyke (left) and Allison Metz (right)

According to Fixsen, the small number of experts in implementation science before NIRN's founding has since increased exponentially, and the field is ready for the next leap forward.

"Melissa Van Dyke and Allison Metz are in a great position to lead NIRN and to lead the next generation of implementation scientists and practitioners," added Blase. "They have been outstanding contributors to implementation science and have gained the trust and admiration of scientists, practitioners, and leaders in human services in the U.S.—and around the globe."

"As I've aged, I've come to realize we're all born into families and groups of associates that have been developing for millennia and will continue to develop after our time has passed," said Fixsen. "I'm proud of what has been accomplished and sad to participate less in the next steps, but I recognize that is the natural course of events. NIRN and the field of implementation are in excellent hands."

Both Metz and Van Dyke expressed their deep appreciation for the mentorship Fixsen and Blase provided to them and for the invaluable foundation on which NIRN can continue to build.

"We feel fortunate to have had the opportunity to work for and learn with Dean and Karen over these last years," said Van Dyke. "It truly is exciting to be a part of this rapidly developing field of study."

"We're delighted to be part of a team of committed 'scientist practitioners'—or 'practitioner scientists,'" Metz added. "We'll continue to learn together and contribute to the growing knowledge and practice base of implementation."

More about FPG's National Implementation Research Network nirn.fpg.unc.edu/

Creators of the Environment Rating Scales Win the Innovator Award

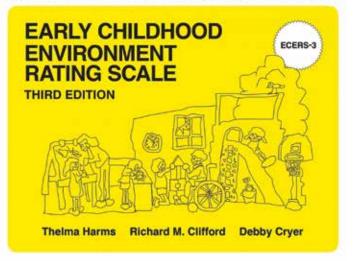
Kaplan Early Learning Company and the Leon & Renee Kaplan Foundation for the Health and Well-being of Children have presented the 2014 Innovator Award to FPG's pioneering creators of the Environment Rating Scales.

At the annual meeting of the National Association for the Education of Young Children (NAEYC) in Dallas, Texas, the foundation honored Thelma Harms, Debby Cryer, and Richard M. Clifford for "forever changing the view of quality care in childhood education."

Best known for their collective work on these internationally-recognized and widely-used assessment tools, Harms, Clifford, and Cryer had debuted their latest addition to the scales earlier the same week at the NAEYC's conference: the much-anticipated new version of the Early Childhood Environment Rating Scale (the ECERS-3), which they designed for classrooms serving 3-5 year-olds.

Since its creation at FPG in 1980, the ECERS and its subsequent versions have become highly popular measures of environmental provisions and teacher-child interactions that affect the broad developmental needs of young children. While developing the ECERS, Harms and Clifford sought feedback from early childhood staff, program monitors, and teacher trainers, as well as thoroughly field testing the scale for reliability and validity.

For much of the 1980s and 1990s, major research projects used the ECERS effectively to evaluate program quality, and the scale also found



significant use in program improvement efforts. In 1998, FPG's Debby Cryer joined Harms and Clifford to co-author a revised edition of the scale (the ECERS-R), which the trio further updated in 2005.

Harms, Clifford, and Cryer developed the ECERS-3 for preschool, kindergarten, and child care classrooms with the intent to provide an easy transition for people already using the ECERS-R. The new scale looks at factors that influence the cognitive, social-emotional, physical, health, and safety needs of children age 3-5, and the authors created it in order to predict child outcomes more accurately and precisely.

The ECERS-3 emphasizes the teacher's role in creating an environment conducive to developmental gains. Subscales evaluate space and furnishings, personal care routines, language and literacy, learning activities, interaction, and program structure. The ECERS-3 also includes additional items that assess math and literacy activities, and, in this new incarnation, the ECERS serves as a stronger tool for distinguishing between "good" and "truly excellent" programs.

As a result, the utility of the ECERS-3 is diverse. The new scale is appropriate for a statewide and district-wide Quality Rating & Improvement System (QRIS) and suitable for use in inclusive settings and culturally diverse programs. Directors and supervisors can tap it for program evaluation, teachers can utilize the new scale for self-evaluation, and agency staff can employ it for monitoring. In addition, the new scale is especially useful for Race to the Top—Early Learning Challenge (RTTT-ELC) research and accountability.

Including the ECERS, Harms, Clifford, and Cryer have developed four different Environment Rating Scales, each designed for a different segment of the early childhood field, including the Infant/Toddler Environment Rating Scale (ITERS), Family Child Care Environment Rating Scale (FCCERS), and the School Aged Care Environment Rating Scale (SACERS). Each scale has proven reliability and validity and embodies a comprehensive perspective on child development. The authors now have offered updated or revised versions of each scale since its original publication. Over the years, the scales have found an international audience of users.

"It's amazing to see how Environment Rating Scales are now being used worldwide to ensure children are receiving the highest quality care and education," said Brenda Leger, Chief Academic Officer at Kaplan Early Learning Company, who praised Harms, Clifford, and Cryer. "Their ideas have changed the way so many people think about child care. They are true difference-makers in our field."

The Environment Rating Scales Institute ersi.info

The ECERS-3 store.tcpress.com/0807755702.shtml

Journal Publishes Special Issue on Pioneer James J. Gallagher

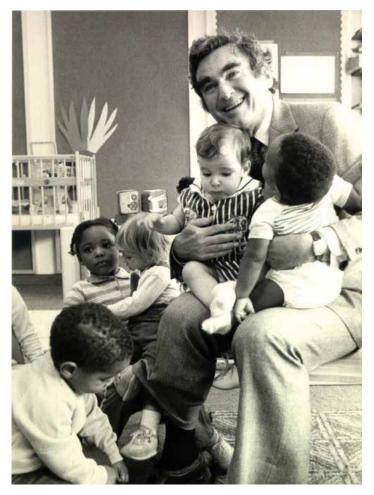
When former FPG director James J. Gallagher died in January 2014, he had long become a beloved and internationally recognized expert on special education and gifted education.

"For many years, Dr. Gallagher was a mentor, colleague, and friend," said FPG director Samuel L. Odom at the time, adding then that the former FPG director was irreplaceable. "With this grief, we also need to remember his great life and achievements."

Dr. James J. Gallagher believed that all children deserved the very best educational opportunities regardless of age, ability, or social status.

Gallagher's career full of awards had continued nearly until the day he died. Just weeks before, UNC's School of Education had honored him with the Peabody Award for his extraordinary contribution to the field of education.

As news of Gallagher's passing spread, many more of his colleagues were quick to note a lifetime of priceless service. Now, the *Journal*



Former FPG director James J. Gallagher in FPG's child care center

for the Education of the Gifted has released an entire issue in tribute to Gallagher's work.

In their introduction for the special issue, the guest editors—Gallagher's longtime colleague and friend Mary Ruth Coleman and daughter Shelagh A. Gallagher—write that "Dr. James J. Gallagher believed that all children deserved the very best educational opportunities regardless of age, ability, or social status. His work addressed early intervention supports for young children and their families, special education services for students with disabilities, and the educational needs of students with gifts and talents."

They also note that Gallagher's research helped to construct a base of knowledge "to support practice, inform policy, and shape educational theories" before adding that his "work encompassed all levels of education... He held that settling for a mediocre education was not an option."

The special issue publishes representative articles from Gallagher with accompanying reflections from experts on the significance of his work: jeg.sagepub.com/content/38/1.toc

"Article of the Year" on Early Childhood Teacher Education is Among Most Read



Last year, the *Journal of Early Childhood Teacher Education* awarded FPG senior scientist Pamela J. Winton, University of Pennsylvania scholar Marylou Hyson, and University of Oklahoma-Tulsa lead author Diane M. Horm with the Taylor & Francis Distinguished Article of the Year. Now the journal's publisher has announced the article was among its most read.

Horm, Hyson, and Winton published "Research on Early Childhood Teacher Education: Evidence from Three Domains and Recommendations for Moving Forward" in a special issue of the journal. Public awareness of the value of high-quality early childhood education has never been higher, as evidence mounts about early education's crucial role in promoting positive short-term and long-term outcomes. Higher education's role in preparing teachers to deliver on that promise is significant and continues to grow, which led to the special issue of the *Journal of Early Childhood Teacher Education* that includes Horm, Hyson, and Winton's award-winning article.

Winton and her co-authors examined studies about early childhood teacher education (ECTE) across three domains: addressing the needs of young children with disabilities and their families; understanding and working effectively with infants and toddlers; and, building young children's competence and interest in mathematics. Each of these domains is critically important in the preparation of early childhood teachers, and programs for early childhood teachers often have underemphasized each of these domains.

Five common themes emerged: accreditation of ECTE programs is voluntary, which has limited the benefits of state and national attempts at quality assurance; there is a dearth of research about the barriers and facilitators for faculty in implementing high-quality college curricula that align with evidence-based practice; pre-service students in ECTE programs receive limited coursework in key content areas, such as working with children with disabilities, caring for infants and toddlers, and teaching math; no system exists to ensure the use of evidencebased approaches in preparing teachers; and, there is little follow-up of pre-service students once they have entered the field.

The authors concluded the field could not yet answer questions about the impact of ECTE programs on teachers or on the children they serve. Horm, Hyson, and Winton called for an environment conducive to collaboration among those who are skilled in qualitative and quantitative research and for a coherent and programmatic research agenda. In addition, they identified needs for a well-prepared pipeline of future ECTE researchers, support from funders and policymakers to build the capacity both to train these researchers and conduct necessary studies, and attention to implementation science in order to help faculty and institutions thoughtfully apply results of research.

Abstract and link to full article

fpg.unc.edu/resources/research-early-childhood-teacher-educationevidence-three-domains-and-recommendations-movi

FPG Study on Infants with Autism Receives Award

FPG fellows Linda Watson, Elizabeth Crais, and Grace Baranek, along with FPG investigator Jessica Dykstra and co-author Kaitlyn Wilson, have received the Editor's Award from the *American Journal of Speech-Language Pathology*. Their seminal article "Communicative Gesture Use in Infants With and Without Autism: A Retrospective Home Video Study" compared the use of gestures in infants with autism to infants with other developmental disabilities or with typical development.

By viewing videos, researchers determined that at 9-12 months infants with autism were less likely to use joint attention gestures than infants with other developmental disabilities or typical development. At this age, infants with autism also were less likely to use behavior regulation gestures than were children with typical development.

At 15-18 months, infants with autism were less likely than infants with developmental disabilities to use social interaction or joint attention gestures, and less likely than infants with typical development to use behavior regulation, social interaction, or joint attention gestures.

The authors concluded "differences in gesture use in infancy have implications for early autism screening, assessment, and intervention."

Abstract and link to full article

fpg.unc.edu/resources/communicative-gesture-use-infants-and-withoutautism-retrospective-home-video-study

FPG Director Odom Leads Special Sesson at the Research Conference of Ireland's National Council on Special Education

FPG director Samuel L. Odom traveled to Dublin last fall to lead a special session on evidence-based programs for children and youth with autism spectrum disorder (ASD) for the annual research conference of Ireland's National Council on Special Education (NCSE). Based in part on Odom's work, the NCSE will give formal policy advice to Ireland's Minister for Education and Skills on the education of students with ASD. As a result, Odom's special session drew interest from Irish newspapers and radio.

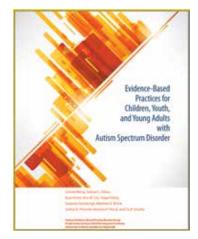
On *Newstalk*, popular Irish current affairs radio programming, Odom explained some of the challenges facing parents with children with ASD, such as "snake-oil salesmen" who hawk unproven treatments, and he emphasized that evidence-based practices can markedly improve children's lives.

For the *Irish Times*, Odom's message included a focus on young adults with ASD who have completed their schooling: "In the US, parents of children with autism face a real challenge when they graduate from high school and go into the community. We do know the outcomes for those individuals are often very poor."

In another article for the *Times*, he termed baseless interventions "the Dark Arts," explaining that "parents want the best for their children and many of these treatments cost lots of money. And to be pulled into a treatment that has very little evidence of efficacy, I think, is a dark thing to do."

While covering a story of how some students with special needs are blocked from entering schools in Ireland, the *Irish Examiner* noted Odom's criticism at the conference of "attempts by some groups to endorse alternative approaches which do nothing and can even damage the children involved." Earlier last year, the National Professional Development Center on Autism Spectrum Disorders had released its much-anticipated update on evidence-based practices for children and youth with autism. FPG scientists spearheaded the project, screening 29,000 articles about autism spectrum disorder to locate the soundest research on interventions for children from birth to age 22.

"More children than ever are being diagnosed with autism," said Odom when the report



was published. "We're catching them earlier, with better tools, and these children need the right services."

Applying more stringent criteria, the NPDC's updated report drops one evidence-based practice from the 24 identified in its 2008 review. After considering more studies this time, scientists also renamed and broadened one category, "technology-aided instruction," and added 5 more, including "exercise" and "structured play groups."

In a press release for the NCSE's conference, Odom explained that the challenge now is to implement evidence-based practices widely. "In the absence of implementation, even the most effective intervention will not yield better outcomes."

The NPDC's report on evidence-based practices for children and youth with ASD

fpg.unc.edu/sites/fpg.unc.edu/files/resources/reports-and-policybriefs/2014-EBP-Report.pdf



The 16th National Early Childhood Inclusion Institute MAY 10-12, 2016

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