Introduction

Nearly thirty years ago, the Robert Wood Johnson Foundation first funded the Local Initiative Funding Partners Program. This unique effort—in which the Foundation shared the funding of promising community programs with state and local foundations—enabled the Foundation to reach deep into communities and nurture ideas that germinated locally.¹

The Local Initiative Funding Partners Program and its successor, the Robert Wood Johnson Foundation Local Funding Partnerships Program, generated many remarkable programs and inspiring leaders, some of whom have been featured in the Robert Wood Johnson Foundation Anthology. These include Jim Kinyon, whose Catholic Social Services brought mental health and substance abuse counseling to the Lakota Sioux living on or near reservations in South Dakota;² nurse practitioner Martha Ryan, who started San Francisco’s only prenatal care clinic for homeless women and saw it mushroom into a $1.7 million operation with thirty employees serving eighteen hundred homeless families;³ and pediatrician Darcy Lowell, whose Child First
program to prevent mental health problems in high-risk children proved so effective in Bridgeport, Connecticut, that it was expanded throughout the state and beyond. These are just a few examples of the kinds of leaders and projects that the Local Initiative Funding Partners Program and the Local Funding Partnerships Program looked for and supported.

In this volume, we are highlighting a Local Funding Partnerships Program effort called the 211 LA County Developmental Screening and Care Coordination Program. Under the dynamic leadership of Maribel Marin, one of its founders, and Patricia Herrera, its director, the program has transformed a traditional telephone helpline (“211”) into a screening and referral service for young children with autism and other developmental disabilities. Since its beginning in September 2009, the program has screened nearly eight thousand children under the age of five; nearly half of them were found to be at moderate to high risk of a development delay.

Digby Diehl wrote the chapter on the 211 LA County Developmental Screening and Care Coordination Program in this volume. A frequent contributor to the Anthology series, Diehl has collaborated on many books, including Rather Outspoken (with Dan Rather); The Million Dollar Mermaid (with Esther Williams); and Angel on My Shoulder (with Natalie Cole). His most recent collaboration is Alone Together: My Life with J. Paul Getty (with Theodora Getty Gaston). It was published in 2013 by HarperCollins.
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“My name is Latonia Jenkins. I have two sons. The oldest, DeMarcus, is three-and-a-half, almost four years old. His brother Amare is eighteen months. Amare is fine, but I called 211 LA because I have some concerns about DeMarcus. He has a very limited vocabulary. He points to things he wants, rather than saying what they are. He says “123 ABC,” but not too much more than that, and he keeps repeating the same things over and over. He doesn’t know how old he is, he can’t tie his shoes, and we’re still working on potty training.”

Roughly one out of six children in the United States has autism, cerebral palsy, a learning disorder, or another developmental disability, but these problems are not evenly distributed throughout the population. They are also not evenly diagnosed. Children from low-income families, particularly ethnic minority children, are doubly vulnerable. Not only are they at greater risk for developmental disabilities, they are also less likely to have their problems addressed in a timely manner.

More than 115,000 of these at-risk children live in the County of Los Angeles. To help identify them and connect them with services, a pediatric developmental screening program was launched in 2009. What makes this program unique is that screenings are not conducted face-to-face in clinics or doctors’ offices, but over the phone by 211 LA County (211 LA), an information and referral call center. Officially known as the Developmental Screening and Care Coordination...
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The 211 LA Developmental Screening and Care Coordination Program, it is the first and thus far the only such program in the nation. Robert Wood Johnson Foundation funding for the program began in 2010 and concluded in 2013.

Patricia Herrera has administered the program since its inception. Fluently bilingual, with graduate degrees in both counseling and psychology, she is an advocate for her program and for the families it serves. “I know it can be a challenge for parents to get help for children with a developmental delay or disability,” she says. “There is always a lot of bureaucracy and red tape to deal with. Having worked in this field for years, it has been my experience that, generally, the parents who are best able to get services are the ones with the most resources. Their English is good. They know how to work the phones; they know how to fill out paperwork. They don’t take ‘no’ for an answer.

“In contrast, many of the neediest families in Los Angeles County do not have these skills or resources. It’s hard, sometimes impossible, for them to get connected with agencies that can help them—those who are most in need are also the most likely to get shut out. These are the families who call 211 LA every day. We have to make the system more equitable, so that the haves and the have-nots are both getting services at the same rate. This program is a step toward that goal.”

A private, not-for-profit 501(c)(3) organization serving the ten-plus-million residents of the Los Angeles metropolitan area, 211 LA fields half a million calls a year. Callers reach out to 211 LA for assistance in dealing with a broad spectrum of life issues, from landlord disputes and problems with disconnected utilities to substance abuse and domestic violence. Operating around the clock seven days a week, it is staffed by approximately seventy specially trained operators called
Information and Referral (I & R) Specialists. They listen to callers describe their situations and then refer them to the appropriate agencies for assistance. Specialists are bilingual (English and Spanish), but information can be conveyed in any of about 140 languages through an on-call interpreting service. The 211 LA call center also serves the hearing impaired.

The center began in Los Angeles in 1981 with support from United Way, and was initially called Info Line. Maribel Marin became executive director in 2002. With a Master's degree in urban planning and extensive work experience in public works and contract administration, she brought a canny business sensibility to the delivery of social services. Early in her tenure, she moved to replace the jumbled collection of toll-free 800 numbers with the all-inclusive 211 designation. “Two-one-one is so easy to remember,” says Marin. “As soon as we converted, we started to be inundated with calls. We doubled our size, and doubled our budget.” With the transition, the service changed its name to 211 LA and joined a fledgling nationwide network of 211 call centers. That network has since expanded to cover more than 90 percent of the US population.

To solidify the financial stability of 211 LA, Marin negotiated sole-source contracts with a variety of government agencies. Funding for the call center is now assured by multiyear agreements with various Los Angeles County agencies, including the Department of Mental Health and the Department of Children and Family Services. In addition, 211 LA is written in as an integral component of the county disaster response network, providing an information resource in the event of an earthquake, wildfire, or other emergency. Marin was able to leverage that designation to procure a generator, paid for by the US Department of Homeland Security, to power 211 LA
headquarters, which is located in what was formerly a savings and loan. “Because we are part of disaster response, we need an independent source of electricity,” she says. “Even if the power goes out—especially if the power goes out—we must be able to keep functioning.”

To offer callers concrete, specific support in time of need, I & R specialists tap into a catalogue of available services. In Los Angeles County, that includes nearly fifty thousand programs administered by five thousand federal, state, and local agencies. In an effort born of necessity, Marin directed her staff to create a comprehensive electronic database of these services to help I & R specialists cut through the tangled web of overlapping programs and jurisdictions.

Called the “Taxonomy of Human Services,” this database functions much like a card catalogue in a library. Just as the nationwide Dewey Decimal System guides readers to the books they want, whether they are searching the vast holdings of the New York Public Library or the stacks at the local community college, the taxonomy gives I & R specialists detailed descriptions of agencies and programs. It is continually reviewed and revised as government programs and eligibility criteria evolve. Maintaining its completeness and accuracy is now a full-time job for five 211 LA staff resource writers.

Because of its consistent, comprehensive listings and descriptions, the taxonomy has been adopted as the national standard by the Alliance of Information and Referral Systems, the accrediting body of 211 call centers. All certified I & R specialists across the country are versed in how to use it. This common organizational framework and common descriptive language enables I & R specialists to pitch in during emergencies taking place hundreds or thousands of
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miles away. This is an essential capability in times of disaster, when local 211 centers can be either swamped by the volume of calls or out of service entirely. When Hurricanes Gustav and Ike hit Louisiana in 2008, calls to overwhelmed 211s along the Gulf Coast were rerouted to 211 LA, together with their local database of services.

Bringing Developmental Screening to 211 LA

Implementation of the pediatric developmental screening program has its roots in the Los Angeles Early Identification and Intervention Collaborative (the collaborative). The collaborative began in the fall of 2003 with a group of ten health and social welfare professionals brainstorming over lunch about how to identify children with developmental delays at an earlier age. Since that first luncheon gathering, the collaborative has grown to become a loose coalition of more than 350 agencies and service providers, including education, public health, and law enforcement, all of whom are affected by the problem.

Jeanne Smart, a registered nurse who heads the Los Angeles County Department of Public Health Nurse-Family Partnership Program, is a longtime collaborative member and former committee chair. “The collaborative came together when it was becoming obvious in every system of care—public health, mental health, school systems, foster care—that there were so many children who were not developmentally appropriate,” she recalls. “All of us were seeing children who were severely developmentally delayed—not rolling over at an appropriate age, not sitting up. Most of them had never been tested, not even the ones who had received some kind of regular pediatric attention. Doctors simply were not doing developmental assessments. They were telling parents of preschoolers—kids who weren’t talking, not even babbling—that their
children were going to be ‘fine.’ This didn’t happen just once or twice; it was chronic. And it is still common today.”

Frustrated by the systemic failure to identify these children, members of the collaborative started exploring alternatives to clinic-based assessment. “The prospect of developmental screening outside the clinic or doctor’s office presented a chance to make a difference,” says Smart, “but the idea of putting it in 211’s lap came from Margaret Dunkle.”

As the catalyst behind the formation of the collaborative and its founding director, Margaret Dunkle had a particular interest in finding a new mechanism to reach underserved communities. “In 2003, we in the collaborative started thinking about policies and strategies that would help us find these children,” she recalls, “but it took more than five years of groundwork to get the effort launched. Developmental screening can be done effectively in a lot of settings. One place where it should be done is during a child’s regular pediatric visit, but we know it’s not being done there.”

Olga Solomon, a University of Southern California researcher specializing in autism, echoes this assessment. “In Los Angeles and across the country, children with developmental disabilities are not getting identified soon enough to benefit from early intervention,” she says. “Even when parents notice the first signs of autism and point them out to their pediatricians, it’s all too common for doctors to discount or dismiss their concerns.”

Some of this may be attributable to the fact that pediatricians, like many physicians, are overscheduled. “In this era of the fifteen-minute doctor visit,” continues Solomon, “pediatricians
complain that they don’t have enough time. And many of them are not well enough connected to resources in the community to know where to refer children who need help, even if they do identify them.”

Although a 211 call center had never been used for pediatric screening, there was a compelling demographic argument in favor of trying to make it work. Out of the half million calls 211 LA fields annually, about 85 percent are from women. More than three-quarters of all callers are Latino or African American. Most are low or very low income—55 percent of them are trying to get by on less than $1,000 a month. More than eighty-four thousand calls per year come from parents with children under the age of five. In short, 211 LA serves the neediest families in the county—the families that are both at greatest risk and least likely to have access to pediatric developmental screening.

The involvement of 211 LA in developmental screening dates from June 2006, when Maribel Marin first attended a meeting of the collaborative. “While we were in the process of converting our phones, transitioning out of the old 800 numbers and into the 211 role, we began to do outreach to inform all of our partners that this was happening,” she says. “At about the same time, the collaborative was going through its strategic planning process. The collaborative approached us because they thought we might be able to help them identify children with developmental delays. We sensed an opportunity. We knew from our caller surveys that we were reaching a large number of lower income families with children under five. We knew that these were families with high psychosocial risk factors. We didn’t know how to do developmental
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screening for young children—yet—but we knew that we had the families that everybody was looking for.”

“This,” says Margaret Dunkle, “was when things started to come together. The following year, federal legislation was amended to require high quality developmental screening in all Head Start programs. Finally there would be a real obligation to address the need that we in the collaborative had seen for so many years.”

At Dunkle’s suggestion, 211 LA asked Patricia Herrera, long a collaborative participant, to head the program. Herrera came to 211 LA from the Frank D. Lanterman Regional Center, one of twenty-one regional centers in California. Regional centers are private, nonprofit corporations that are run under the auspices of the State Department of Developmental Services; they work with individuals who have lifelong developmental disabilities.

Herrera initially joined the 211 LA developmental screening program as a consultant; her first responsibility was to find a way to fund it. With assistance from Dunkle, she began writing grant applications. In December 2008, the W. M. Keck Foundation awarded 211 LA a start-up grant of $300,000. “We knew that children were not getting screened until they were in kindergarten or first grade,” says Dorothy Fleisher, program director for Keck’s Early Learning Program. “By that time, they were already years behind. Beyond the importance of the program, however, we were very impressed with the dynamic leadership of 211 LA.”
With initial funding assured, Herrera was officially named director of the Developmental Screening and Care Coordination Program. The Weingart Foundation provided a one-year grant of $106,000 in June of 2009. “This was an opportunity to support an area of work that the Weingart Foundation has long been interested in,” says Belen Vargas, the foundation’s vice president of programs. “It was a chance to really address some of the issues concerning how and why it has been difficult to get young children screened. There are so many lost years during which intervention services could have changed their story.”

The Robert Wood Johnson Foundation became involved in 2010, when its Local Funding Partnerships Program awarded the program a three-year grant of $500,000. (The Keck Foundation served as the program’s nominating funding partner.) “We wanted to test the model to see whether people would call in to 211, and to see whether families would be able to get screened and then be connected with service providers,” says Pauline Seitz, director of Local Funding Partnerships. “Our goal was to learn whether this was a model that would work in a community as large and complex as greater Los Angeles.”

**Early Intervention—the Stitch in Time**

Why are early identification and early intervention so important? Biomedical research has proven that by the age of three, 80 percent of human brain development is complete. The very young brain adapts and responds to new stimuli, which makes the ages from birth to five, and in particular the ages from birth to three, the prime time to help a child who is exhibiting signs of developmental delay or autism. The window of opportunity starts to close thereafter, limiting not only the chances of success, but also the amount of improvement that can be achieved. “The
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benefits of early identification and early intervention are huge,” says Charles Sophy, Medical Director for the County of Los Angeles Department of Children and Family Services. “The first five years are the key time frame to lay the foundation for all of the stuff that goes into making a solid human being—trust, integrity, self esteem. The younger the age, the more positive impact intervention will have.”

“Early intervention,” says Margaret Dunkle, “is often the critical stitch in time that can make a huge difference in a child’s development.” Autistic children in particular benefit greatly from intensive early intervention. Recent research shows that not only can it improve their language and social skills, it can also actually normalize brain activity. As autism researcher Olga Solomon says, “It literally may make the difference between a child who grows up to assemble and pack boxes in a sheltered workshop, and a child who goes to college.”

Developmental Screening

Developmental screening at 211 LA begins with what might be considered a typical 211 call.

“You’ve reached 211 L.A. This is Linda. How can I help you today?”

“My name is Yolanda Zamora. I need to find housing right away for me and my son.”

“I can assist you with that, Ms. Zamora. What is your current situation?”

“I’m in a shelter. I left home because my husband is doing drugs. He’s been getting into fights, even when Javier, our son, was watching. I didn’t feel safe anymore.”
The first priority of the I & R specialist is to take care of the original stated reason for the call. Beyond responding to the original request, the specialists are trained to probe for unstated needs. Callers asking about food assistance may also get information on how to file for Medicare or Medi-Cal, or for veteran’s benefits, or how to get immunizations or a flu shot. And even when the caller doesn’t volunteer the information, all I & R specialists routinely ask whether there are children under the age of five in the home. “People who are struggling often do not have a real understanding of what services are available,” says Herrera. “We give them as many resources as we can, and while we’re at it, we ask them about their kids. That’s what makes the developmental screening model so powerful, because it flows from their own original request.”

So after Linda helped Ms. Zamora get connected with resources for permanent low-income housing, she gently asked about her son:

“While I have you on the line, Ms. Zamora, may I ask whether you have any concerns about how your son is developing?”

“Yes I do, actually. It’s very hard to understand what Javi is saying. I’ve already brought it up with his pediatrician, but the doctor said she didn’t see anything wrong.”

Linda then offered Ms. Zamora the opportunity of getting a developmental screening for Javier, eventually patching her through to one of 211 LA’s care coordinators. I & R specialists do not follow a script, but there are protocols in place for dealing with each type of call the center receives. This includes a standard procedure for handing off a caller to a care coordinator for developmental screening, making a “warm transfer” whenever possible. If a care coordinator is
available, the specialist makes the introduction and passes the caller on; the interaction briefly becomes a three-way conference call:

“This is 211 LA County. My name is Cheryl. How can I help you today?”

“My name is Graciela Flores. I need help getting back-to-school supplies for my child.”

“I’d be happy to assist you with that, Ms. Flores. May I have your zip code, please?”

“91106.”

“That’s Pasadena. I can give you a list of places where you will be able get backpacks, notebooks, and other supplies. Will your child also be needing immunizations?”

“Yes.”

“Okay, Ms. Flores, I will also be giving you a list of clinics where you can get the immunizations that your child will need for school. While I have you on the line, Ms. Flores, do you have any concerns about how your child is developing?”

“I do, actually. Miguel is four years old and he’s not talking in complete sentences.”

“Ms. Flores, 211 Los Angeles County offers developmental screening for children under the age of five. If you are interested in that screening, I can connect you with one of our care coordinators.”

“I am interested, yes.”

“Ms. Flores, I’m going to put you on hold briefly while I contact one of our care coordinators. Please stay on the line . . . .

Ms. Flores, I have Nancy, one of our care coordinators, here. She will help you with the developmental screening.

Nancy, this is Graciela Flores. Her son Miguel is four years old.”
“Good afternoon, Ms. Flores. My name is Nancy. I understand that you are concerned that your son may have speech problems . . . .”

As the developmental screening program was gearing up, the team had to decide what screening methodology would be used. Margaret Dunkle believed that a parent questionnaire developed by Frances Glascoe, a professor of pediatrics at Vanderbilt University, could be adapted for use by 211 LA. Called PEDS (Parents’ Evaluation of Developmental Status), the screening test consists of a series of standardized questions designed to elicit parents’ concerns about how their child is progressing.

The PEDS test has two critical assets: brevity and accuracy. Just ten questions long, it detects 70 to 80 percent of a wide range of developmental and behavioral issues. Although PEDS had already been rigorously tested and validated, it had never been administered by phone before. Its use by 211 LA would break new ground.

Glascoe consulted with 211 LA on the use of her model throughout the first three years of the program. She believes that phone screenings actually offer some distinct advantages. “When doing the assessment over the phone, the care coordinator can encourage the parent to give a lot of information. We’ve found that parents are eager to talk about their children. If a mother says that her son is three years old and hyperactive and doesn’t sit still for a minute, the care coordinator will take note of that, even if the parent says she is not concerned about it.”
Care coordinators, all of whom are bilingual, must have a college degree in early childhood education or in some aspect of social work, psychology, or family therapy. They must be familiar with risk conditions for developmental disabilities, and must have some direct counseling experience. It is also essential that they possess excellent listening skills and a great deal of empathy; they need to be able to make parents feel comfortable talking about their children, particularly if the parent suspects there may be a problem.

Care coordinators are trained to project a phone personality that is warm and conversational—professional, but never clinical or judgmental. Nancy Godoy, who helped Ms. Flores in the situation above, began her career in case management at Harbor Regional Center and has been a care coordinator with the 211 LA developmental screening program since it began. “We make sure that the caller feels heard, and that we are addressing what he or she believes is a concern. Many parents who call us, particularly younger parents, do not have a good grasp of what constitutes age-appropriate development. For this reason, speech and communication problems are often the first issue to get their attention.”

As the screening proceeds, care coordinators continually feed the parents’ responses back to them: “Okay, Ms. Flores, what I hear you saying is . . . .” This gives the parent the opportunity to correct or clarify any misunderstanding, and also to add additional information. “At first I was very surprised by how much parents would tell me over the phone,” says care coordinator Irene Aceves. “People share things about their household, their family, the way they are living their lives. Mostly, though, they like talking about their kids.”
What do care coordinators listen for? “There are things a parent might say that would raise a flag,” says Nancy Godoy. “When a mother says, ‘He’s in his own world,’ I will ask whether she can tell me more. If she says, ‘I can’t handle him anymore. He’s out of control,’ I might say, ‘Let’s talk about the behaviors. What is he doing exactly? How often is he doing it? Is it just with you, or is it at school?’ Sometimes it’s the parent who needs some parenting skills. Other times, there really is something going on with the child, and the child needs intervention, or the child has a condition that needs to be diagnosed.”

Care coordinators also have to “listen between the lines,” says Godoy. “We can’t focus solely on a child’s speech difficulty, even if this is the parent’s primary reason for calling. Being behind in language development could be a speech problem in and of itself, but it could also be an indicator of other issues. We need to understand why the child is behind. We have to take into account everything that’s going on in the child’s life.”

**Neither Diagnosis Nor Prescription**

As soon as the screening is completed, care coordinators share and discuss the results with the parent. Following their established protocol, they speak to the child’s strengths first, before addressing the problems. Coordinators then work with the parent to develop a plan of action. “We work it out so that there is a consensus between the family and the coordinator,” says Patricia Herrera, “with the coordinator using her best informed judgment about what will work for the family.”
Herrera is careful to point out that screening and referral constitute neither a diagnosis nor a prescription. “From that perspective, 211 LA has always been protected from liability,” she says. “We are simply providing parents with options, and informing them about how to pursue them. We say that if the screening finds something, there's reason for you to be concerned, and doctors and clinicians should take a closer look at your child.”

Care coordinators are always mindful that the results of the screening may be difficult for a parent to hear and accept. “There's a denial that's to be expected,” says Irene Aceves. “Veronica was a parent I screened almost a year ago. I referred her to a Head Start Early Education program, to her local school district, and to a regional center, because there were a lot of concerns. She followed through just with the Head Start, but actually that was great, because once you get into Head Start, they also do a screening. The staff there started telling her that her son needed further testing. Just last week she called me back. ‘You know what, I’m embarrassed,’ she said. ‘I’m ready for the referral to the regional center now’”

For Latonia Jenkins, the mother at the beginning of this chapter, the results were surely not what she was hoping to hear. Although she suspected that DeMarcus, her older son, had developmental problems, she didn’t initially have concerns for her younger son, Amare. But after Amare’s screening, she learned that he had failed the autism screening test. Faced with two children with developmental disabilities, Latonia decided to “think a little” about whether to accept the referral to a regional center.
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Patricia Herrera nevertheless remains hopeful for the family. Like Veronica, Latonia Jenkins was connected to a Head Start, where both of her children will receive assessments. “Our goal is not to get everyone to a regional center,” says Herrera. “Our goal is to get these children the services they need.”

Care coordinators offer resources to parents even when the screening does not indicate a significant risk of developmental delay. Paula Dinkins, a student, called 211 LA because she was looking for low-income housing for her family and for child care for her two young children. After the I&R specialist provided her with that information, Dinkins accepted the chance to do a developmental screening with Irene Aceves. She admitted that she was somewhat concerned because Curtis, her two-year-old son, was throwing tantrums and displaying aggressive behavior.

Although neither Curtis nor Emily, his older sister, was found to be at risk for developmental delay, Dinkins did eventually reveal what might be part of the problem: she and her children were living with her parents, who had stopped admitting Dinkins’ day-care provider into their home. This was why she was looking for low-income housing. “I have night classes,” she says. “I often don’t get home till 11:00 p.m. I just want my kids to sleep in their own beds at night.” Irene Aceves was able to connect Dinkins with parenting classes to help her cope with Curtis’s tantrums and aggression.

Care Coordination—Active, Hands-On Referral

Once the screening is completed, care coordinators need to deploy an additional set of crucial skills. “Our care coordinators must understand how social services are delivered,” says Maribel
Marin, “and in Los Angeles County, that can be very complicated. To be able to help someone over the phone, you have to know how to work the system.”

In the words of the 211 LA Web site, care coordinators “locate, refer, broker, monitor, expedite, provide advocacy, and coordinate fragmented services offered by professionals and organizations from different disciplines. They also provide information and coaching to parents and caregivers on navigating the service system.”

Political geography, combined with the situations of the callers, can make the care coordinator’s task more difficult. Los Angeles County is a crazy quilt of jurisdictions with irregular boundaries, including incorporated cities, unincorporated areas under direct county governance, and school districts. Who is responsible for delivery of services to an at-risk child is often dependent on the family’s place of residence, but many callers to 211 LA don’t have a permanent address. Often it’s part of the reason they’re calling; they could be staying in a motel or a shelter, or couch surfing, or they may be living in their car.

Moving frequently and not having proof of residence can be a serious barrier to receiving services, and it is a problem that care coordinators frequently have to overcome. Learning how to connect at-risk children to resources effectively takes specialized study. “Our care coordinators go through a rigorous five-week training program before they get on the phones,” says Marin, “but training doesn’t ever really stop. We have anywhere from two to ten hours a month of follow-on training to keep everyone on top of what’s happening.”
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One of the much-recognized facets of the 211 LA developmental screening program is the hands-on connection of families with service providers. Care coordinators direct their families not just to an agency, but to a particular person in the agency. Whenever possible, they are on the line with the parent when that connection is made. The process is in many ways parallel to the warm transfer between the I&R specialist and the care coordinator that precedes the developmental screening.

“With referrals from clinics and physicians, there is a general tendency not to follow through,” says Vanderbilt’s Frances Glascoe. “Often they don’t make the recommendation strongly enough, or they just hand families a phone number. That just never works. What 211 LA does is stay on the phone with the family when they make a referral. They link them live to Head Start, to Early Start, to regional centers. Their uptake is more than twice that of primary care providers.”

“Here at 211 LA,” says Patricia Herrera, “we know that if you tell a mother her child may have a developmental problem, you better know where to send her. We not only give her a referral, we’ll tell her who she’s supposed to see, what papers she’ll need to bring, the hours the office is open, and what buses she’ll have to take to get there. If she needs a bus fare, we’ll tell her how to get it. That’s what care coordination is.”

And it doesn’t stop once the referral has been made. Coordinators stay in touch with the family, not just to make sure that the referral handoff has been successful, but also to buttress the
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health and stability of the family as a whole. On average, care coordinators make seven follow-up calls with the families they have screened. “We stay in contact,” says care coordinator Godoy, “Until we know they are receiving some kind of intervention services—preschool, mental health, speech therapy, assessment at the regional center. We also invite them to call us. We are working in partnership to help their child.”

A Performance-Driven Organization

The 211 LA developmental screening program sprang from the cooperative efforts of the many agencies participating in the Early Identification and Intervention Collaborative. Once the program was launched, Marin and Herrera built on that legacy of teamwork, working with and through the collaborative to establish a strong network of partnerships with service providers.

The program has cemented those partnerships with memorandums of understanding (MOUs). Although nonbinding, the MOUs codify how the agencies work together. Partner agencies commit to taking 211 LA referrals and providing outcome information, and 211 LA commits to doing the screening and to providing care coordination and a care plan for the family. Partner agreements are in place with all seven regional centers in Los Angeles County, with the Los Angeles County Office of Education, and with a number of Head Start and Early Head Start providers. More are pending.

The MOUs are “the acknowledgment that we both have the same mission: to find these children and serve them,” says Herrera. “We have real relationships with our partners—we did a lot of meaningful work together before we had the piece of paper.”
Much of this “meaningful work” involved laying the groundwork for a relationship of trust. Before committing to take referrals from 211 LA, receiving agencies had to have confidence not just in the integrity of the screening process, but also in the ability of care coordinators to make sure that the families they refer are qualified to receive services. “Assessment and early intervention can be costly,” says Marin. “A comprehensive assessment at a regional center involves a physician, a clinical psychologist, and a speech therapist. The cost averages $8,000 per child. With that kind of expenditure, our partners need to know that we aren’t sending them families who don’t match their eligibility criteria.”

211 LA’s extensive data collection and analysis system helps to reassure its partners. From the outset, 211 LA has made data a priority. “We are a performance-driven organization, so we know that operations need to be driven by outcomes—and for that you need data.” For the developmental screening program, 211 LA developed its own software to track information about parents participating in the program, as well as about care coordination. New information is automatically integrated into 211’s existing electronic database, allowing 211 LA to follow the children it refers to the partner.

The Road Ahead

After nearly a decade of screening and making referrals, those responsible for LA 211 have gained many insights. “I think the first lesson we learned,” says Herrera, “and it was a big question at the outset, is that families, even in their most stressful situations, still want to talk about their children. The tool that we use allows us to have those conversations in a very compassionate, caring way, so that families feel connected to us, and are willing to take the
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next step.”

The second lesson came from an unforeseen statistic. Approximately 70 percent of the parents who accepted the offer of developmental screening didn't initially make contact because they were concerned about their child's pace of development. Most, like Yolanda Zamora looking for housing or Graciela Flores in search of school supplies, called for other basic needs.

Above all, the 211 LA developmental screening program confirmed the great number of children in need of early screening and intervention. The results from the first four years of the program—from September 2009 through June 2013—are striking. Of the 7,816 children whose parents completed the screening, more than half were found to be at moderate to high risk for developmental delay or disability, and almost a quarter were identified as being at high risk. This is roughly twice the rate found in the population as a whole. And of the more than 4,800 children screened for autism, 16 percent were found to be at high risk, a rate one and a half times greater than the national rate. For most of these families whose children were identified as being at risk, the findings were completely unexpected—only about a third of parents who participated had expressed concerns about their child's development before the screening took place.

211 LA would like to expand, but does not yet have the budget to offer screening to all parents of young children who call in. “We get seven thousand callers with children under five each month,” says Patricia Herrera. “At present we are screening between 10 and 12 percent of them. It’s a drop in the bucket, but our capacity is limited because at present we can only carry three
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care coordinators on staff.” The philanthropies that originally backed the 211 LA developmental screening program are no longer funding it. Financial support for the program now comes primarily from a grant from First 5 LA, a county commission that is funded by California’s tax on tobacco products. Although support from First 5 will sustain the screening program at its current level for the near future, Marin and Herrera are exploring a number of alternatives that would eventually give the program greater financial independence.

The first is by forging partnerships with universities and other research institutions. Academic researchers know that good data are hard to come by. For them, the trove of information 211 LA receives from its high volume of callers, coupled with its built-in system for electronic collection and analysis, is a mother lode. For 211 LA, published research papers based on its aggregated data are expected to offer a real opportunity to enhance the credibility and reputation of the developmental screening and care coordination program. “Our university partners have seen the potential for this to be a best practice,” says Herrera. “It’s a win-win.”

The program is now expanding its partner relationships to include universities and research institutions. In 2013, it began a new partnership with the UCLA Kaiser Permanente Center for Health Equity. The first step is a study conducted by Bergen Nelson, an assistant clinical professor of pediatrics at UCLA and former Robert Wood Johnson Foundation Clinical Scholar, that will utilize 211 LA’s data to evaluate the effectiveness of the developmental screening and care coordination program. “We understand the value of performance- and evidence-based practices,” says Marin. “Within 211 LA, we already have great confidence in the effectiveness of
our model, but there is a difference in perception between our saying what our data show and UCLA independently confirming what our data show. We anticipate that their rigorous analysis will validate our model. At that point, we will be in a stronger position to increase our screening capacity and attract more government support.”

In addition to the relationship with UCLA, 211 LA has established similar data-sharing agreements with several of its community partners, including the LA County Office of Education, Head Start, and all seven regional centers in the county. The organization is in discussion with several other institutions, including the University of Southern California and Children’s Hospital Los Angeles. Other cities have also approached 211 LA about replicating the program outside California. There have been exploratory discussions with cities in Pennsylvania, Michigan, and Missouri.

One of the first efforts at replicating the developmental screening model may take place within 211 LA itself—but with a different target population. Marin is looking to adapt the pediatric developmental screening model to other populations, including veterans and, through Head Start, homeless families who have children in need of early intervention. “After homeless shelters make a referral, care coordinators will do the screening,” says Los Angeles County Head Start Director Keesha Wood. “They will automatically refer them to Head Start. We will start working with them, and then give that information back to 211. It’s a program that has great potential. If we can make it work successfully here in LA, which is huge, we can be a model for other communities.”
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A key objective in securing the future of the 211 LA developmental screening program is to tap into reimbursement funding based on federal and state mandates. “We’re trying to focus on the programs that are already allocating money for the activities that we think we can do better,” says Herrera. As part of its partnership with UCLA Kaiser Permanente, 211 LA is looking to undertake care coordination for several of its pediatric community clinics. “We know that pediatricians do not have the infrastructure to organize screening for low-income families, nor do they have the ability to offer care coordination,” says Marin. “We already have a system in place that is efficient and consistent—and we can track data.” Because these clinics are publicly funded, 211 LA would be positioned to receive reimbursement under both Medi-Cal and the Affordable Care Act. The Individuals with Disabilities Education Act (IDEA) offers another possible revenue stream. The law stipulates that children with disabilities are entitled to early intervention and special services that are designed to prepare them for further education. Each state is charged with implementing a comprehensive, coordinated effort to provide services.

Through a provision called Child Find, school districts are required to be active in identifying all children who need early intervention. In California, the state’s program to address their Child Find obligation is called Early Start. “It is a funded mandate,” says Herrera, “but there has been a lack of coordination among agencies receiving Child Find monies. Bureaucracies tend to work in isolation, in silos. It’s very inefficient, both in terms of identifying children and in terms of best use of resources.”

Conclusion
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There is broad consensus among child development experts that pediatric screening should be universal for all children. “The earlier the identification, the earlier the intervention, the better the outcome,” says Maura Gibney, family resource manager of the South Central Los Angeles Regional Center. “With the right early intervention by occupational therapists and physical therapists, we can often make up the delay. We can set these children on the road to a full and productive life.”

“The greatest potential for 211 LA lies in its ability as a single organization to marry screenings with referrals to services,” says Paul Chung, associate professor of pediatrics and chief of general pediatrics at the David Geffen School of Medicine and Mattel Children’s Hospital at UCLA. “Screening is worthless unless you can get people connected to services, and getting people connected to services is worthless unless we can figure out who needs to get connected. That’s the magic that 211 has the potential to deliver. For a large number of families who have been left out of access to these services, 211 might turn out to be their best bet.”

The implications of revamping the approach go far beyond developmental screening. With the adaptation of the model to use with veterans and with homeless families, the 211 LA developmental screening program suggests a new, more efficient, more effective way to integrate service providers and find economies of scale in the process. As 211 LA says on its Web site, they are looking toward “changing the system, one child at a time.”
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Notes

1 Latonia Jenkins is a pseudonym, as are the names of other callers in the chapter.
