Wednesday, April 9th, 2014 – OGR Subcommittee hearing:
"Examining Ways the SSA Can Improve the Disability Review Process"

Ms. Jennifer Lockhart, State Director, Sooner SUCCESS,
The University of Oklahoma Health Sciences Center

Note: All times EST

On behalf of Sooner SUCCESS and every individual with disabilities I am here today. I am here today to speak with you about the state of our existing system. I am here to tell you it does not work. I am here to tell you why. You might ask what positions me to speak out so strongly about what I believe to be one of the most undignified supports we have in our great country. I have seen it first hand, I have lived it. From the moment my family adopted four children with special needs over 30 years ago to the moment I stand here today. I have witnessed it up close and personal.

First let me tell you about Sooner SUCCESS. Sooner SUCCESS was piloted over ten years ago by Dr. Mark Wolraich. At that time, Dr. Wolraich left Vanderbilt University for the University of Oklahoma, to fill the chief of developmental behavioral pediatrics Shaun Walters Endowed Chair, also known as the University of Oklahoma Child Study Center. Dr. Wolraich realizing the same struggles existed in Oklahoma for families he treated at Vanderbilt created Sooner SUCCESS. Sooner SUCCESS was developed on a complex adaptive systems (CAS) approach allowing local coalitions to address their unique needs. We believe Sooner SUCCESS does exactly this through advancing an inclusive comprehensive unified, system of health, social, and educational services for Oklahoma children with special healthcare needs or chronic illnesses within their community, Sooner SUCCESS embeds multiple levels of service delivery seamlessly

so families can address both immediate and long term goals through an adaptive approach. Through this approach, we are not only able to analyze the multiple systems (educational, health, social) families struggle to navigate, but also, mobilize the system as warranted within the community when needed through adaptive change agents. This is where our local coalitions and county coordinators are tremendous assets. Change is inevitable, so we must organize the system in a way adapting to change but also educate providers, caregivers, self-advocates, and patients to understand an ever evolving system instead of multiple independent static structures or agencies. Anecdotally speaking we believe this model works. We see this in observation in articles such as the recently published Newsweek article titled The Health Gap: The Worst Place in America for Mental Health, Child Poverty and College Attendance Mapped: The article ranked counties in each state. Of the Top ten counties in Oklahoma five are Sooner SUCCESS Counties and part of the original pilot program ten years ago. Last year alone, in 2013 Sooner SUCCESS made over 31,537 community linkages in our 13 pilot counties. Our 13 counties consist of Tulsa and Oklahoma City, Oklahoma's two most populated cities and 11 rural communities. Within these demographics we are able to serve close to half of Oklahoma's children with disabilities ages newborn to 21. We often serve transitional years between 18-24 as well. With that said, you could say we have a pulse on the grass root level, the view from the balcony as to what our communities look like, each very different with very unique needs. We are your eyes and ears on the ground. What does the view from the balcony look like? A victim of unintended consequences our system designed to assist individuals with disabilities is paralyzed by multiple levels of dysfunction.

For the sake of understanding why, we will understand Sooner SUCCESS. Sooner SUCCESS based on CAS, a complex adaptive system model facilitates adaptation on the local level. Unlike typical service delivery programs, Sooner SUCCESS challenges the current system and integration process as well as the complex systems within which integrated care is enacted. In regard to disability services, integrated, comprehensive care has not developed widely nor as quickly as we hoped. We believe this is because integrated care is not a **program but a process**. Why is this important you might ask? Let me explain further. "…findings indicate that integration is challenged by:

- system complexity,
- weak ties and poor alignment among professionals and organizations
- a lack of funding incentives to support collaborative work
- a bureaucratic environment based on a command and control approach to management

Further, and I quote from a recent publication in the International Journal of Integrated Care "lack of systems change towards integration is that we have failed to treat…the system as complex-adaptive system. The data suggest that future integration initiatives must be anchored in a CAS perspective, and focus on building the system's capacity to self-organize. **We conclude that integrating care requires policies and management practices that promote system awareness, relationship-building and information-sharing, and that recognize change as an evolving learning process rather than a series of programmatic steps"**. What does this mean on the system level and what does it have to do with our

issues here today? It means that unless the system is fluid and adaptive we leave it vulnerable. Those vulnerabilities expose themselves through certain outcomes, mostly gaps in service, system exploitation, duplicative services, and fragmentation or dissonance in services. Those vulnerabilities also tell us what often numbers cannot, what the system looks like from real life application. So in real world terms what does that look like?

In the words of our Oklahoma County Coordinator, Lori Wathen proud democrat and mother of a child with Down syndrome:

"I am tired of seeing those who need help unable to get it, because people who don't need it are using the system…we see it every day"

From Donald Baily of S.C.

"I am testifying at a hearing next week in DC presenting testimony regarding disability reform and Social Security. In my testimony I will be discussing the higher Ed piece and referencing your work with the CTC and the S.C. model. I just wanted to be sure this was OK?

Donald's reply: Good for you! Of course you can… tell all, thanks!

Donald is a former trustee with the University of South Carolina, father of a son with Autism, and founder of the South Carolina College Transition Connection, a consortium of five universities in S.C. providing Higher Ed options for individuals with intellectual/ developmental disabilities. Donald and his wife, along with other parents created the CTC because they wanted something more for his son than sitting at home after he aged out of the system.

I have chosen Donald and Lori and could provide you with many more parent and provider statements as to barriers in the system. The bottom line is due to the many gaps we have created a pervasive problem in which we have left not only the system vulnerable but the individuals we are to be helping. We see children with impairments labeled disabled, we see parents and adolescents remain under employed so they may sustain their benefits. We see thousands on a wait-list in Oklahoma who receive no services because they are “waiting” for “assistance”. Aside from service gaps, we see something more concerning. Deeply concering. We see people with disabilities unknowing segregated from their communities because the transition from the school support service stops often when the individual ages out of the system. Services stop, the support system is gone instantly and because transition services are programs rather than processes we see individuals who should be out in their communities go from an active community life, that being their school, to nothing. Almost overnight. In observation we are able to see a gap where most young adults with disabilities should be transitioning into the community. Why weren’t they in their community all along? Like you and me? People with disabilities deserve to be a part of our community, a natural part, not guests. And those programs while intended to be helpful...turn people away rather than towards each other. The "turning towards each other" ...is our instinctive way of facilitating integration one with another. When we impede this fundamental human transaction...we unknowingly stop the natural process of inclusion-to some extent. The family and the individual can become dependent on the services if they are not gradually removed over time preparing the person for more independent living. This is not an agency problem as much as it is a systems problem and reform is essential to change. Most agencies are merely trying to implement the parameters

placed before them. However, this change includes better definitions of disabilities, understanding the differences between disability and impairment, and instigating a convergence between the two parallels of commerce, community and independent living with government support services. This will require fundamental change not only in how we perceive disability but how we support individuals, specifically children, with disabilities.

Lastly, as we move forward in the spirit of transformation understanding this is not a partisan issue. It is not a bi-partisan issue. It is a non-partisan issue, a civil rights issue, a human rights issue and lastly a dignity of life issue. It is our responsibility to prepare all individuals for independent living, to be productive contributing citizens of society. This is the root goal of education and individuals with disabilities deserve more than what we have in place now. Change will require efforts of both the public and private sectors working in tandem. Through a sound joint process we can create a system equally welcoming to all. In closing I want to share a quote with you from one of our Successforlife Foundation Trustees:

Sooner Success is filling a significant need, to support Oklahoma Families secure the resources needed to access and achieve the American Dream, of enjoying a life that fulfills one's aspirations. Children with disabilities deserve the opportunity to grow up to be productive adults in society and secure gainful employment. Employers who recognize the value of all types of diversity in the workplace, will be the ones who enjoy a win/win experience, in achieving their corporate goals. I am proud to be associated with the U.S. Chamber of Commerce, who recently stated that, "greater access and opportunity for individuals with disabilities, will also be beneficial to business."

----Charles H. Van Rysselberge, President, CVR Consulting, LLC, in Charleston, SC (former President & CEO of the Oklahoma City and Charleston, SC Chambers of Commerce).

Former Greater Oklahoma City Chamber President Charles Van Rysselberge, one of the founding minds of Oklahoma City's Cinderella story. Charles returns to Oklahoma City after a decade of absence as a trustee of the SUCCESSforlife Foundation. Charles was recently honored by the National Chamber of Commerce Executives, with a lifetime membership award for his innovativeness and ingenuity essential to thriving communities. Through his work with the Atlanta Chamber, Oklahoma City Chamber and Charleston, SC Chamber, he has brought revitalization to systems and infrastructure, the life blood of communities. Charles understands the business of business. He also understands to attract businesses, you first must attract families. Charles teaches at the US Chamber-Institute for Organizational Management and is a graduate of the "Diversity Leadership Academy" sponsored by the Riley Institute at Furman University. A key focus of the Diversity Leadership Academy is to educate individuals on the value of diversity in the workplace...in solving workplace and corporate problems through the benefits of a diverse workforce.

STATE HEALTH POLICY

Briefing

A PUBLICATION OF THE NATIONAL ACADEMY FOR STATE HEALTH POLICY

FEBRUARY 2012

Oklahoma's Web Portal: Fostering Care Coordination Between Primary Care and Community Service Providers

BY LARRY HINKLE AND CARRIE HANLON

STATE HEALTH POLICY BRIEFING PROVIDES AN OVERVIEW AND ANALYSIS OF EMERGING ISSUES AND DEVELOPMENTS IN STATE HEALTH POLICY.

This is the second in a series of Assuring Better Child Health and Development (ABCD) III issue briefs focusing on promising methods participating states are using to improve care coordination and linkages among providers of primary care and other community services for young children and their families. This brief describes the new web-based referral and tracking system that Oklahoma built into its pre-existing Preventive Service Reminder System (PSRS). The state designed this web portal to improve care coordination for children with or at risk for developmental delays. The web portal is being used in the state's four ABCD III pilot counties. The state is already considering ways to adapt the web portal to coordinate care for other populations.

The ABCD program is funded by The Commonwealth Fund, administered by NASHP, and designed to assist states in improving delivery of early child development services for low-income children and their families. The program assists states by strengthening primary health care services and systems that support the healthy development of young children. Since 2000, ABCD has helped 27 states create models of service delivery and financing through a laboratory for program development and innovation. The ABCD III Learning Collaborative began in October 2009. For more information about ABCD visit: http://nashp.org/abcd-history.

NATIONAL ACADEMY for STATE HEALTH POLICY

Through the Assuring Better Child Health and Development Learning Collaborative (ABCD III) five states (Arkansas, Illinois, Minnesota, Oklahoma, and Oregon) are enhancing child development by improving care coordination and linkages among primary care providers (PCPs) and other providers of community services for young children and their families.[1] The ABCD III state initiatives began in 2009, and a number of early lessons have already emerged.[2]

A key feature of the Oklahoma ABCD III project is the adaptation of an existing statewide information system as the basis of a web-based mechanism ("web portal") for pediatric and community providers to make and track referrals for low-income children identified as at risk of developmental problems. The web portal is built into the state's pre-existing Preventive Services Reminder System. Currently, pediatricians, Early Intervention specialists and public health officials in four communities are testing the online system. The goal is to expand the use of the web portal to pediatric providers across the state as well as to explore its implementation to assist other populations served by Oklahoma's Medicaid program. The lessons from Oklahoma's ABCD experience in implementing a web portal outlined in this brief may inform the efforts of policymakers in other states as they strive to improve care coordination. They include:

- Provide clinic staff with the appropriate training needed to successfully operate a web portal upfront, along with ongoing technical assistance following implementation. Use hands-on practice facilitation to tailor and advance the implementation of technology in practices and referral sites.
- Develop information-sharing mechanisms that meet federal privacy protections.
- Partner with community stakeholders to ensure continued success.
- Collaborate/partner with a university.
- Look at existing web-based tools and infrastructure to see if they can be enhanced for care coordination.

Introduction

Oklahoma's ABCD III project, Connecting the Docs: Improving Care Coordination and Delivery of Developmental Screening and Referral Services in Oklahoma, aims to advance systemic changes designed to improve outcomes for young children with and at risk for developmental delays. With the support of the state project team, four communities (Canadian, Garfield, Pottawatomie, and Tulsa counties) are piloting interventions to improve care coordination and communication of referral outcomes between primary care and community service providers. Each community has a core team representing primary care practices, Early Intervention agencies, local health departments, care coordinators, and family support (via the Oklahoma Family Network – a family-to-family health information center).[3] These county teams meet regularly to strengthen relationships and to work with state partners to identify community needs and fine-tune improvement strategies identified by the state team.

The project uses a multi-faceted "Facilitated Change" strategy to implement practice-based interventions. A key component of this strategy is two Practice Enhancement Assistants (PEAs or practice facilitators) who are based out of the University of Oklahoma Health Sciences Center. The PEAs support participating primary care practices as they implement the interventions conceived of by the state ABCD III team.[4] The PEAs help practices conduct Plan-Do-Study-Act (PDSA) cycles, which are four-step, rapid cycles designed to test and analyze the impact of improvements on a small scale. The PEAs also provide technical assistance to help practices use resources developed by the state team. The PEAs have been critical in both developing and nurturing the county teams during the pilot process. Foremost among the resources the PEAs have helped practices and community service providers implement is a web-based referral and tracking system or "web portal," which is meant to create: 1) an infrastructure to coordinate isolated

Table 1 – Key Partners in Oklahoma

Partner	Agency and Description
Early Intervention	**SoonerStart** is Oklahoma's Early Intervention (EI) program. SoonerStart is a joint effort of multiple state agencies, however, the Department of Education is the Lead Agency for EI.
Care coordinators	**Sooner SUCCESS** provides care coordination for families, providers, and communities. Sooner SUCCESS sits in the Child Study Center Program at the University of Oklahoma Health Sciences Center. (See "University").
Local health departments	Through the **Child Guidance** Program, local county health departments provide services to children and families including assessment, intervention, consultation, and education. The program is within the Oklahoma State Department of Health.
Family support	The **Oklahoma Family Network** (OFN) is a family-to-family health information center that provides peer support to parents of children with medical issues or disabilities. OFN also provides support groups for parents raising children with special needs or a disability.
Medicaid agency	The **Oklahoma Health Care Authority** houses the state's Medicaid program, which is known as SoonerCare.
University	The **University of Oklahoma Health Sciences Center (OUHSC)** provides technical support for the Preventive Services Reminder System. OUHSC also supports Practice facilitators (Practice Enhancement Assistants) who provide technical assistance to the ABCD III pilots.

initiatives designed to ensure follow-up for referrals, linkages of subsystems, and monitoring of process and outcome measures; 2) a consistent single point of contact or service provision infrastructure across communities; and 3) a process to assure that families of children at risk for delay are connected with appropriate services.

Web Portal Infrastructure

The "web portal" is the mechanism participating pediatric practices and community partners in pilot counties use to initiate, follow-up on, complete, and communicate information about referrals for early childhood services in Oklahoma. The Oklahoma ABCD III team developed the web portal by building it into the pre-existing Preventive Services Reminder System (PSRS). PSRS is an open-source academic system designed and maintained by the University of Oklahoma Health Sciences Center (OUHSC) Department of Family and Preventive Medicine. OUHSC designed PSRS to help primary care practices improve preventive and longitudinal care. Preventive care recommendations are based on U.S. Preventive Services Task Force (USPSTF) guidelines.

PSRS was originally designed for networked Palm® handheld devices. The device would remind primary care providers (PCPs) to ask patients about past preventive services and current risk factors. The system is now accessible via a web browser from any web-enabled device, and it contains a number of elements and tools for PCPs including: an immunization registry, a secondary preventive services registry, visit and patient-specific recommendations at the point-of-care, data exchange with the state immunization registry, and routine data collection for practice-based research.[5,6] The Agency for Healthcare Research and Quality (AHRQ) and the Medicaid agency (Oklahoma Health Care Authority) first funded the PSRS in 2002, and it has since been funded by a series of grants from the National Institutes of Health (NIH).[7] The PSRS started as a way to track immunizations, but as it developed further, the state decided to add the capability to track well-child visits since they fit so closely with vaccine periodicity.

As a part of the Oklahoma ABCD III project, OUHSC has developed and added a new component to the PSRS: a "Request for Early Childhood Services," also known among project participants as the "web portal."

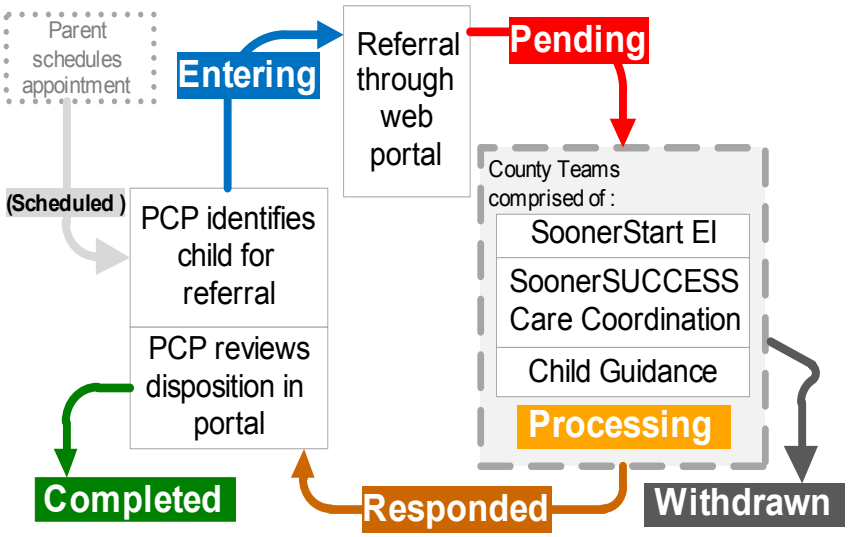
How it Works: Oklahoma's Linkage Process

The web portal was designed specifically with the goal of improving care coordination for children with, or at risk for, developmental delays.[8] The service linkage process in Oklahoma starts when the parent schedules an appointment for a child with a PCP. If the PCP is participating in the ABCD III pilot process and identifies a child with, or at risk for, developmental delays (for instance, concern about a motor delay), the PCP will enter a request for referral through the web portal. At this time the web portal shows the referral as **pending**. There are usually few pending requests in the web portal at a given time because referral agencies respond within 24-48 hours. This response time is due to statutory guidelines for Early Intervention that dictate that the agency must begin an initial response within two days.[9]

Once in the system, county-specific teams receive an email flag alert that a referral is pending. These county teams are composed of: Oklahoma's Early Intervention (EI) Program; Sooner SUCCESS care coordination program (a collaboration between the OUHSC Child Study Center and the Oklahoma Department of Human Services); and Child Guidance (within the Oklahoma State Department of Health)(see Table 1). The agency most appropriate to meet the child's needs triages the request for referral. Though the county teams had the option to choose which agency was the first to triage the request for referral, all four county teams – independently of each other – opted to have EI be the initial triage point.

When the appropriate agency receives and triages the request, the web portal lists the referral as **processing.** The appropriate agency then sends information around eligibility and what services the child will be receiving back to the PCP through the web portal, which then lists the request for referral as **responded** (for instance, undertaking an assessment that identifies motor delays that qualify the child for Early Intervention services, and a plan for physical therapy services to address the delay). At this point the PCP receives an email flag from the portal with a notification about the request for referral. The PCP then reviews the information sent back from the county team. Once the PCP indicates in the portal that s/he has reviewed the information, the referral process is **completed** (i.e., the primary care provider now has information in a medical record that indicates that the child is under the care of a physical therapist to address motor delays). The web portal does allow for a request to be **withdrawn** if the referral

Figure 1. Oklahoma's linkage process[10]



was entered in error (i.e., a duplicate entry). For a map of the care coordination process please refer to Figure 1.

Implementing the Web Portal

The Oklahoma ABCD III team is aware that in order for the web portal to be sustainable, it must meet the needs of those it serves. To successfully implement the web portal, the ABCD III team has relied upon both clinic support and community collaboration. By implementing the web portal this way, the ABCD III team has been able to facilitate clinic adoption of the web portal while also remaining receptive to feedback from community partners.

Clinic Support

The Practice Enhancement Assistants (PEAs) mentioned previously work closely with participating primary care practice clinicians and staff to integrate the web portal into their everyday routine. The PEAs also provide technical assistance for the web portal. The PEAs train clinic employees on the web portal functions and provide IT support for installing the security certificate/user names/passwords for the web portal. Once the web portal is running, the PEAs remain available to offer technical assistance on the issues detailed above. They initially visit each clinic once every two weeks and provide additional support via telephone and email as needed. The Oklahoma ABCD III team has found that once the initial implementation is complete and the web portal is in use, requests for support decline quickly, from one or two minor questions a week, to one or two minor questions a month. Oklahoma estimates that one PEA can manage approximately 150 practices after they are fully operational with the web portal.

Community Collaboration

The Oklahoma ABCD III team has responded to feedback on the design of the portal since the beginning of the project. Counties and practices have significant latitude to determine how they will respond to requests within the web portal – there is no one formal method across the state. This flexibility is critical to the project's success, as each county team can use the web portal in a way that is tailored to its specific individual, personnel, workflow, and population needs.

The ABCD III team also acts on suggestions for modifications to the web portal to make it more useful to the county teams. Changes to the web portal made as a result of community feedback include:

- the ability to search both by county and by referral, which enables PCPs to limit the search only to those who they have referred;
- the addition of a feature where PCPs can "hover" over a patient's name with the mouse in order to see a quick snapshot of actions taken to date; and
- a secure messaging feature that allows direct communication between clinics and community teams.

The ABCD III team has also worked closely with its community partners to ensure that all participating team agencies or

organizations have access to the web portal. Since family support professionals are not medical providers, the ABCD III team is collaborating with state partners to provide the necessary privacy (i.e., HIPAA) training prior to granting Oklahoma Family Network (OFN) team members access to the web portal. To date, one OFN representative has received this training, and the team is in the process of training more. Simultaneously, the ABCD III team is fine-tuning consent forms to clarify which community partner organizations have access to the web portal.

By being open to feedback, the Oklahoma ABCD III team has made the web portal more useful and practical to practices and community teams, which helps ensure that it will be used beyond the duration of the project.

Advantages of the Web Portal

The web portal seeks to minimize the time and effort needed to initiate, track, and follow-up on referrals. Prior to its development, PCPs in Oklahoma did not have a standard tool to make referrals for early childhood services and receive feedback on those referrals. The web portal now serves that purpose. The project team originally intended to create a paper-based fax-back form. With a paper form, the burden is on the PCP to write in the child's demographic information and identify the appropriate referral agency. In contrast, the web portal pre-populates most of this information for the PCP; it includes the demographic information for all children enrolled in the state's Medicaid primary care case management program (SoonerCare Choice).[11] An interagency agreement between the state Medicaid agency (Oklahoma Health Care Authority) and the University of Oklahoma Health Sciences Center facilitates this data sharing.

The university pre-populates the web portal with local county team information. Therefore the PCP does not need to identify the referral agency or a specific contact at an agency. The web portal automates this process. Further automating the process, the state is developing a dual HIPAA/ Family Education Rights and Privacy Act (FERPA) form for families to sign to ensure that a PCP with HIPAA approval can receive information about a child from Early Intervention.

Another advantage of the web portal is that it helps eliminate duplicate screening. PCPs are able to upload the results of developmental screening from the Ages and Stages Questionnaire (ASQ) and attach them to the referral in the web portal. They can also elect to document ASQ screening scores only, without attaching a scanned instrument. This expedites the referral process for families by clarifying when Early Intervention does not need to screen the child and can move straight into in-depth assessment.

Furthermore, the web portal and its associated email alerts enable pediatric practices to stay informed about follow-up services provided to patients by Early Intervention and community service providers. Without the web portal, pediatric providers might not know the results of a given referral, including whether the child was assessed, if the child qualified for services, and/or whether the child is receiving support services.

In addition to minimizing the burden on PCPs, the web portal also facilitates the state's ability to monitor and evaluate the model. The web portal indicates completed feedback loops (in which the PCP refers a child for services and receives information about the results of the referral) and provides the screening/referral documentation necessary for billing purposes.[12] The design allows the Oklahoma ABCD III team to electronically review web portal usage to measure trends in referrals and track the average length of time a referral stays in each stage of the process by participating county. This information helps the ABCD III team identify any bottlenecks in the system or areas where additional improvement may be needed to help close the feedback loop.

Financing

The initial Preventive Services Reminder System was funded by a grant from the Agency for Healthcare Research and Quality (AHRQ) with additional support provided by the Oklahoma Medicaid agency, and began in 2002. Since 2004, however, the PSRS has been funded through a Career Development Award (K08), which was awarded to the developer by the National Institutes of Health. Since the child development piece of the PSRS and the web portal enhance the usefulness of the program, the K08 funds were able to be used to build the web portal into the Preventive Services Reminder System. ABCD III grant funds were used to support the pilots. The state is using ABCD III funds, as well as funds from a medical home contract, to fund the practice enhancement assistants. The activities of the web portal are closely aligned with medical home activities within the state.

Results to Date

The ABCD III team has been tracking the use of the portal in each of the four pilot communities as it has been

implemented. As of September 2011, there were 177 requests for referral in the web portal. Of these 177 requests, 85 percent (150) resulted in feedback to the primary pediatric provider, which is considered substantially higher than standard practice. Of this 85 percent of referrals for which there was pediatric feedback reported, about 75 percent (112) of the referrals were officially completed by the agency and reviewed by the pediatrician; 25 percent (38) showed that the local agency had determined eligibility and/or services and were awaiting pediatric provider review in order for the referral to be declared "completed." An additional 12 percent (22) were processing, whereby the county team had received the referral from the pediatric practice and were undergoing the assessment to determine eligibility and services. The remaining referrals (about 3 percent of total requests) were either pending county team review (1) or withdrawn due to error (4).[13] The state ABCD III team has found that the information flow process to date has, thus far, been useful and exciting for the participating communities.

Data from a previous University of Oklahoma Health Sciences Center project ("Helping Family Physicians Screen and Identify Children At-Risk for Developmental Delays")[14], which was funded by the Association of University Centers on Disabilities (AUCD) and the Centers for Disease Control and Prevention (CDC), included 862 chart reviews in three clinics. The chart reviews showed wide variability in the practices' results, but overall, primary care providers identified 47 children as having or being at-risk for a developmental delay; they referred 14 of these children to Early Intervention, and they had information concerning the outcome of the referral for 8 of those 14 children. The aggregate result is documented feedback to primary care providers in 17 percent of charts (8 out of 47 children), which is much lower than the web portal data to date of 85 percent (150 out of 177 children).

Statewide Implications for Care Coordination

Oklahoma's ABCD III team offered each of its pilot counties the option of using the web portal or the paper-based fax-back form. Some of the practices were hesitant to use the web portal at first; but after hearing positive feedback about the portal, all four pilot counties chose to implement it. Oklahoma has experienced declining state budgets and increased financial pressure in the wake of the recession. The notion of providing more efficient care coordination (i.e., simplifying referrals for PCPs, and eliminating duplication of efforts) makes it very attractive to the practices.

In an effort to sustain and spread the successes of ABCD III, the state is looking to capitalize on the popularity of the web portal within the pilot practices by sharing it with others outside of the ABCD III pilot who may find it helpful. The project team has found a lot of interest in the web portal within the state. A demonstration of the web portal within the state Medicaid agency (Oklahoma Health Care Authority) drew more than 60 personnel.[15] Many attendees saw the portal as having uses and implications beyond ABCD III. Beyond child development, agency staff sees the web portal as an opportunity to potentially improve care coordination and service linkages for mental health and substance abuse services, among other ideas.

The ABCD III team is exploring these other uses/implications to ensure the sustainability and spread of the project. One potential future use of the portal for sustainability may be incorporating its use into Oklahoma's medical home program, which provides enhanced payment to primary care practices that varies based on increasing levels of medical home capacity. In addition, the state Chapter of the American Academy of Pediatrics is exploring ways for the practicing physicians to earn Maintenance of Certification (MOC) credit if they learn the web portal system. Maintaining certification is required for pediatricians every ten years.[16]

Lessons Learned

The Oklahoma ABCD III team has learned a number of lessons while developing and implementing the web portal.

- **Provide the appropriate training up front, along with ongoing technical assistance following implementation.** The PEAs devoted significant time to training individual practices at implementation. The training was tailored to each individual practice so that the web portal would best fit with that practice's workflow. The PEAs' demonstrations and assistance with implementation and IT issues helped address some initial concerns in some practices about using a new tool (the web portal) while they were implementing other technology, such as electronic medical records. The PEAs have remained involved post-implementation and provide continued technical assistance.

- **Develop information-sharing mechanisms that meet federal privacy protections.** Oklahoma developed security certificates to ensure only authorized persons have access to the portal. These certificates dictate which computers can access the portal. This greatly increases security and makes the portal a secure, HIPAA compliant, web-based framework. The state also developed a dual HIPAA/FERPA consent form to ensure that a PCP with HIPAA approval can receive information back from Early Intervention. With this form in place the state was able to add boxes to the web portal to indicate that HIPAA and FERPA consent are on file.
- **Partner with community stakeholders to ensure continued success.** The Oklahoma ABCD III team has been very accessible and receptive to the practices and county teams piloting the web portal and this has resulted in positive feedback. The state has listened closely to feedback from community partners on what would make the portal more useful and made revisions to meet their needs. Examples of these improvements include the addition of check boxes at the bottom of the response page to indicate whom among the four partners touched the referral during the process and the addition of gentle guidance cues in the web interface to prevent and educate about system mismanagement, yet are minimally intrusive to workflow.[17]
- **Collaborate with a university.** The Oklahoma Medicaid agency's partnership with the University of Oklahoma Health Sciences Center is extremely fruitful and has been fundamental to the development and success of the web portal. Based out of the university, the practice facilitators have been instrumental in the implementation and continued technical assistance of the project. The university benefits from this partnership by learning more about the dynamics of early childhood referrals that can be used in the future to design and study similar interventions that improve the quality of care. Additionally, work on the ABCD III project informs and enhances university researchers' past and current research on child development.
- **Look at existing tools to see if they can be enhanced for care coordination.** As mentioned earlier, the PSRS, developed with funding by AHRQ and the Medicaid agency, was already considered a useful and well-accepted tool among PCPs. The Oklahoma ABCD III team was able to build the web portal into this already existing system, simultaneously improving its functionality and supporting care coordination. Other states should look at existing resources upon which to build an electronic system to facilitate referral and follow-up among various providers. Immunization registries, for example, might provide a useful platform from which to begin to build a care coordination information system.

Conclusion

Oklahoma's web portal has emerged as an effective tool to coordinate care and share information across multiple providers on referrals and follow-up services for young children within four communities. Furthermore, the web portal's popularity has ensured not only its success in all of the pilot counties, but has also garnered interest from other stakeholders as well. The Oklahoma ABCD III team plans to use this interest to support its sustainability and spread throughout the state. The state plans to provide continued support for the web portal to make it more valuable to practices. Additionally, the state plans to explore avenues for expanding the web portal to other populations with the knowledge that doing so will likely ensure not only the web portal's survival and spread beyond the project but also advances in care coordination more broadly.

Endnotes

1 For more information about ABCD III please visit the National Academy for State Health Policy's (NASHP), "About ABCD III" page: http://nashp.org/abcd-history.

2 C. Hanlon and J. Rosenthal, *Improving Care Coordination and Service Linkages to Support Healthy Child Development: Early Lessons from a Five-State Consortium*. (Portland, ME: The National Academy for State Health Policy, June 2011). Available online: http://nashp.org/publication/improving-care-coordination-and-service-linkages.

3 For more information about the Oklahoma Family Network visit: http://www.oklahomafamilynetwork.org/.

4 Hanlon and Rosenthal, *Early Lessons*, pg. 19.

5 Z. Nagykaldi and J. Mold, "The Role of Health Information Technology in the Translation of Research into Practice: An Oklahoma Physicians Resource/Research Network (OKPRN) Study," *The Journal of the American Board of Family Medicine* 20 (2): 188-195 (2007), pg. 189. Available online: http://www.jabfm.org/cgi/content/full/20/2/188.

6 Oklahoma Physicians Resource/Research Network, "Preventive Services Reminder System (PSRS)." Accessed 8/31/11. Available online: http://www.okprn.org/psrs.html.

7 *Ibid,* pg. 33.

8 For a thorough explanation of the web portal and how it fits in the Preventive Services Reminder System please see the presentation by Zsolt Nagykaldi, Assistant Professor of Research and Clinical IT Specialist, at the University of Oklahoma Health Sciences Center, in *Tracking Linkages: A Closer Look at Data tools in Minnesota and Oklahoma*. Available here: http://www.nashp.org/webinars/abcd-eval-workgroup/lib/playback.html.

9 Oklahoma State Department of Education, "SoonerStart Early Intervention Policies and Procedures," *The Individuals with Disabilities Education Act (IDEA) Part C: Program for Early Intervention Services*, pg. 16. Available here: http://sde.state.ok.us/curriculum/speced/pdf/SoonerStart/Publications/EI_Manual.pdf.

10 Oklahoma ABCD III Team, "Connecting the Docs: July 2011 Project Update." Presentation, *ABCD III: Improving Care Coordination, Case Management, and Linkages to Support Healthy Child Development Summer Learning Collaborative Meeting*, from Burlington, VT, July 18, 2011.

11 If the child is not enrolled in SoonerCare Choice the PCP can still use the portal, but must enter that child's demographic information.

12 Oklahoma ABCD III Team, "Connecting the Docs: July 2011 Project Update." Presentation from Burlington, VT, July 18, 2011.

13 Oklahoma ABCD III Team, "Connecting the Docs: 7/1/11 – 9/30/11 and Annual Report Combined." *ABCD III Project Report*. Submitted by Oklahoma ABCD III team to NASHP in October, 2011.

14 Research Topic of Interest #: 2008-02-18. Visit: http://www.aucd.org/template/page.cfm?id=356 to view archive with project abstract.

15 Oklahoma ABCD III Team, "Connecting the Docs: July 2011 Project Update." Presentation from Burlington, VT, July 18, 2011.

16 Providers must reach MOC requirements to remain board certified by the American Board of Pediatrics (ABP); practices can conduct quality improvement projects that meet the standards set by the ABP in order to maintain certification. Oklahoma is also exploring the option of setting use of the web portal as a tool that could help PCPs achieve medical home recognition. For more information please visit: https://www.abp.org/ABPWebStatic/?anticache=0.37695307220874186#murl%3D%2FABPWebStatic%2Fmoc.html%26surl%3D%2Fabpwebsite%2Fmoc%2Faboutmoc%2Fmaintenanceofcertification%28moc%29four-partstructure.htm.

17 Oklahoma ABCD III Team, *ABCD III Progress Report*, October 2011.

NATIONAL ACADEMY *for* STATE HEALTH POLICY

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SCIENTIFIC

An Innovative Oklahoma Program to Coordinate Interdisciplinary and Interagency Services for Children with Special Healthcare Needs at a County Level

Mark Wolraich, MD; Jennifer Lockhart, BS; Louis Worley, MS

ABSTRACT

Children and youth with special health care needs (CYSHCN) and their families often require multiple services from multiple providers in order to meet their needs. The Sooner SUCCESS (State Unified Children's Comprehensive Exemplary Services for Special Needs), was developed based on a complex adaptive systems approach allowing local coalitions to address their unique needs. Sooner SUCCESS provides support to families and service providers at the community level including a broad range of supports from simply helping a family identify and access a service that already exists to innovatively marshaling generic resources to meet a unique need. The program uses these family support activities coupled with the Community Needs Assessment to identify local service needs encouraging community capacity building by coordinating the efforts of the health, mental health, social and education systems to identify service gaps and develop community-based strategies to fill those gaps.

INTRODUCTION

Children and youth with special health care needs (CYSHCN) and their families often require multiple services from multiple providers in order to meet their needs. Families find themselves continually negotiating a complicated network of federal, state, local and private service systems that are governed independently and allocated through different sets of eligibility standards. Oklahoma's information and referral system currently lists on their web page over 105 services under developmental disabilities, 123 services under mental health and seven different categories for financial assistance.[1] For families and providers, figuring out how to access these services is often difficult and providers tend to focus on their specific areas of expertise. A provider within a specific service discipline may be very aware of the access mechanism for their own system, but unaware of how to get services from another system or even the availability of those services. Services in Oklahoma, like many other states, are organized within funding streams and along condition specific lines. Families and providers have difficulty navigating these service systems. Often a family must describe their child in one way to achieve access to services then in another, sometimes opposite, way to get the kind of service they need (i.e. special education provided in an inclusive setting). Providers are faced with many of the same obstacles as families and have the additional challenge of managing the flow of services from their own agency. It is extremely difficult to blend resources across different sectors such as education and health.

In addition to the inadequacy of the system to meet the families' needs, the systems are frequently very inefficient. Since it is difficult to determine the broad needs of CYSCHN, there are gaps in services in many cases and duplication of services in other areas. To keep costs down different sectors try to put in place measures that keep their costs manageable. As examples, in the past, CYSHCN often have been excluded from participation in managed care schemes and private health insurance coverage because both generally exclude people with preexisting conditions. Sectors such as education and health have each tried to limit their burden by designating services as ones that should be provided by the other sector. There are few structures in place that can facilitate the coordination of services so that they maximize efficiency and equitably divide the burden between different service sectors. As a recent example, the present need for intensive behavioral services for young children with autism[2] places a burden on both the education and health sectors, with no mechanism for the sectors to arrange to share the burden.

CYSHCN are often excluded from participation in managed care schemes and private health insurance coverage because both generally exclude people with preexisting conditions. A higher percentage (12.3%, compared to 8.8% nationally) of Oklahoma's CSHCN were without insurance at some point during the past year. 19.8 % of Oklahoma families responding to the survey indicated that they experienced financial problems due to their child's health needs (National Survey of CYSHCN Chartbook, 2005-06). The higher Oklahoma teen birth rates (which exceed the national average by almost 12 percentage points OSDH, 2003) are also a factor. The rate is higher in rural Oklahoma. Teen births coupled with the uninsured rate in some rural counties of over 37% and expected poor outcomes can seem daunting. A solution is needed that maximizes existing resources, fills shortfalls with innovative answers, enlists the energy of consumers and providers and other community members collaboratively and crosses condition-specific boundaries.

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The long-standing acknowledgement of the importance of interdisciplinary, interagency coordination of services for CYSHCN has stimulated a variety of improvement efforts in different human service sectors. However, implementing such services has been a challenge. A review published in 2007[3] identified the following 6 principles: (1) responsive to family challenges, priorities, and strengths; (2) developed in partnership with constituents; (3) reflective and respectful of the cultural norms and practices of the families participating; (4) accessible to everyone; (5) affordable to those who need assistance; and (6) organized and coordinated through collaboration so that resources are equitably distributed in an efficient and effective manner. They defined the macro level changes of: (1) standardized eligibility protocols developed jointly by the federal and state agencies contributing funds to the system; (2) legal and accounting mechanisms or vessels for blending (flexible use) funding streams; (3) development of cost-sharing mechanisms to allocate costs fairly among families, private insurers, government, and other payers; (4) measures to eliminate duplication of effort based on resource allocation procedures developed through intergovernmental agreements; and (5) a flexible point of entry such that a family need only apply once, with this application appropriate for all needed services. The micro level needs to include families, physicians, other health and mental health care providers, local schools, public transportation, and social service providers. The micro level also needs to include the creation of operational interagency collaborative relationships such that families access services when they need them. The creation of community grants or other incentives to encourage coordination across delivery agencies and providers, including the Medical Home to facilitate the arrangements and a local governing or organizing structure to help achieve this goal.

Historically, a majority of these initiatives have employed one-dimensional, "top-down" or "imposed" approaches. The major initiatives are change efforts such as new programs applied within a single human service sector rather than across multiple sectors. For example in the health care sector projects have been initiated in the primary care setting aimed at improving the screening of children for developmental delays or increasing their ability to provide Medical Home components. While these traditional efforts have resulted in some improvement, they often achieve only modest gains in integrating services.

Factors likely contributing to the less than desired level of improvement include: 1) the complex and frequently changing requirements of families and CYSHCN which pose significant challenges to designing an integrated system flexible enough to meet individual needs adequately; 2) the inability for the complex systems at a local level to form effective coordinating systems across agencies and sectors; 3) the ever changing current health care financing model with a number of unreimbursed costs of care and coordination serving as a strong disincentive to change. [4] In the absence of a coordinated system, families who must access human service systems frequently in order to provide the best care for their CYSHCN are often left on their own to navigate the complex array of different professional disciplines and agencies, each of which may have different and often conflicting eligibility requirements and financing options. Like others[5,6], we have attempted to begin to address the issues from the perspective of complex adaptive systems in order to achieve a more coordinated human service system for CYSHCN and their families. This approach requires focusing at the local level with a program that allows for the organizational development to be sensitive to the unique aspects of each county particularly with regard to existing community relationships, facilitates and adapts the process through a county coordinator (service navigator) not tied to a specific local agency, includes a communication structure between local community programs and agencies at a state level and provides a motivational system at the local level to help to encourage ongoing activities is likely to result in the more extensive local coordination and better and more extensive services.

The Sooner SUCCESS (*S*tate *U*nified *C*hildren's *C*omprehensive *E*xemplary *S*ervices for *S*pecial Needs), Oklahoma's Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs (CYSHCN) was developed based on a complex adaptive systems approach. The Sooner SUCCESS pilot project began as a coalition of family members, mid-to upper-level public service managers and advocacy groups met to discuss how Oklahoma could address service gaps and lack of interagency coordination across both public and private service systems not only at the state but at the community level. It began in 2002 with initial funding from the Department of Human Services Title V and a grant from the Oklahoma Developmental Disabilities Council. The initial program consisted of 6 county coalitions formed in 2002 and expanded to 9 in 2006, to 11 counties by 2010 and currently is in 12 covering about half of Oklahoma's children.

Sooner SUCCESS provides support to families and service providers at the community level including a broad range of supports from simply helping a family identify and access a service that already exists to innovatively marshalling generic resources to meet a unique need. The program uses these family support activities to identify local need. The infrastructure established at the local level supports community capacity building based on those needs. Sooner SUCCESS builds community capacity by coordinating the efforts of the health, mental health, social and education systems, identifying existing public and private services, identifying service gaps and developing community-based strategies to fill those gaps.

Families, educators, social and health professionals and others are provided a structure by Sooner SUCCESS to connect with one another in ways that multiply their capacity and effectiveness. This infrastructure provides the mechanism to integrate the system services provided by health, mental health, social and educational agencies supporting CYSHCN and their families. Sooner SUCCESS partners with family members, local communities, the Oklahoma Developmental Disabilities Council, Oklahoma State Departments of Human Services (OKDHS), Education (OSDE), Health (OSDH), Mental Health

and Substance Abuse Services (ODMHSAS), Rehabilitation Services (ODRS), Health Care Authority (OHCA), Oklahoma Commission on Children and Youth (OCCY), Office of Juvenile Affairs, (OJA), Oklahoma Leadership Education in Neurodevelopmental Disabilities (LEND) and the Center for Learning and Leadership (UCEDD).

Members of each coalition represent families, the OKDHS, OSDE, OSHD, and ODMHSAS. Regional and state coalitions consisting of similar elements plus representatives from ODRS, OHCA, OCCY, OJA, the UCEDD, the LEND and the Section of Developmental and Behavioral Pediatrics at the University of Oklahoma Health Sciences Center.

Members of each coalition represent families, the OKDHS, OSDE, OSHD, and ODMHSAS. Regional and state coalitions consisting of similar elements plus representatives from ODRS, OHCA, OCCY, OJA, the UCEDD, the LEND and the Section of Developmental and Behavioral Pediatrics at the University of Oklahoma Health Sciences Center.

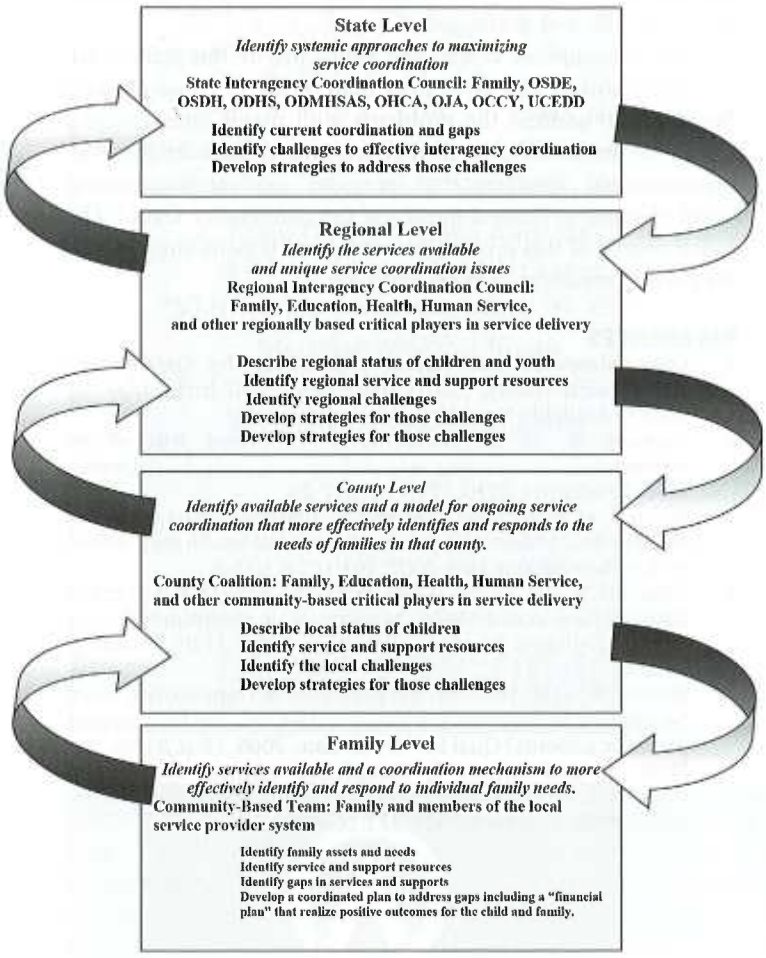
Each participating county was provided a half time coordinator to facilitate the development of their county coalition and provide navigation at the request of any families or family providers in their county. As an initial step, they determined all the services within their county so they can advise the families who request services when possible. Where they are unable to find a solution, they bring the requests to their coalition to help come up with a plan to address the need. In addition, the coalitions are provided with information from a bi-annual needs assessment that includes information specific to their county and information about the nature of the referrals that their coordinator received. The process provides information and motivating forces to each coalition to find innovative solutions to their needs and a forum whereby resources across agencies can be braid to most efficiently and effectively meet the families' needs. Identified issues which are broader than a local county can also be raised to the regional or state levels as needed. The support provided by Sooner SUCCESS to families and service providers at the community level include a broad range of services, from simply helping a family identify and access a service that already exists to innovatively marshalling generic resources to meet a unique need. The program uses these family support activities coupled with the Community Needs Assessment to identify local needs. It supports community capacity building by coordinating the efforts of the health, mental health, social and education systems, identifying existing public and private services, identifying service gaps and developing community-based strategies to fill those gaps.

The model project established an infrastructure for the pilot region that facilitates community-based capacity development through ongoing comprehensive interagency coordination and collaboration among families and service providers at four levels as depicted in **Figure 1**:

- **State Level:** The Sooner SUCCESS State Interagency Coordination Council has membership from families, State Departments of Health, Education, Human Services, Mental Health and Substance Abuse Services, Rehabilitation Services, Health Care Authority, Commission on Children and Youth, UCEDD, LEND and OU CSC. This group identifies current interagency coordination activities, challenges to effective interagency coordination and builds capacity to address those challenges through policy and/or procedural adjustments. The Sooner SUCCESS State Interagency Coordination Council meets monthly and also provides guidance to the project.
- **Regional Level:** A regional team made up of key public, private and family community leaders and project staff identifies the services available and unique service coordination issues within the multi-county region. A needs assessment process supports the regional team members in service assessment and service gap identification. The Community Needs Assessment identifies regional assets and challenges. The regional team is supported by a Regional Coordinator who also is responsible for support and guidance to county coordinators. The Sooner SUCCESS Regional Coordination Council meets monthly to accomplish regional capacity development and provide guidance to the Regional Coordinator. It provides an opportunity for counties to share their successes and challenges.
- **County Level:** At the county level, two components of the infrastructure were established. Coordinators in each county assemble a coalition of family members, education, health, mental health and social services and other community-based stakeholders. The county coordinator facilitates the project goals at the community level. The county coordinator and the coalition are charged with identifying available services and a model for ongoing service coordination across the county. The county coalition uses the Community Needs Assessment to develop community-based capacity building initiatives. The county coalition meets monthly.
- **Family Level:** The fourth level may be the most critical. Individual families, the county coordinator, coalition members and/or other community members can bring families, either literally or figuratively, to the monthly coalition meeting and ask the group to resolve service needs that one or more of the service agencies are unable to meet or the family can not otherwise access. The county coalition identifies services available and a coordination mechanism to more effectively identify and respond to individual family needs. The team identifies family assets, services needed, service gaps for individual families and develops a coordinated plan. Information generated by this process is communicated to the other levels within the model as one mechanism to determine need. Specifically, when a service gap is discovered, resolution is sought at local, regional and state level, whichever is appropriate.

The program was started with Title V funds and a developmental Disabilities Council Grant in order to develop the first 6 county coalitions to the northwest of Oklahoma City in suburban and rural counties. It further developed with an US Maternal and Child Health Bureau Systems Integration Grant expanding

Figure 1. Sooner SUCCESS Structural Organization



to three additional counties including Tulsa and several surrounding counties. As time limited grants have ended, it has continued with some State support as well as funds from the Commonwealth Fund, the Oklahoma Health Care Authority, the Department of Education and continued DHS Title Five funds so that there are now 12 county coalitions covering over half of the state's children.

RESULTS OF ACTIVITIES

Services to Individual Families

The coalitions have been meeting monthly since their inception with anywhere from 10 to 30 attendees representing human services, mental health, education health and families. Between 2007 and 2012 the program helped 3,048 children with 1,498 of those in the past two years. These children were within 2,585 families with 1,294 in the past two years. While county coordinators (navigators) mostly served the families in their county, 215 of those served were from out of the county which provided the service.

As Specific Examples of Individual Family Navigation Activities:

1. A county coordinator (navigator) in one county worked with the Department of Rehabilitation Services, Department of Human Services, a home improvement store, a local fund for children with special needs and a volunteer community group who donated the labor to provide a home bathroom wheelchair accessible modifications for an eight year old boy with spina bifida who wanted to be independent in his toileting.

2. A single mother with a son who was the product of an extremely difficult delivery that resulted in his having visual and intellectual impairment was referred to the county coordinator (navigator) in her county when her son was 2 years of age. The navigator was able to facilitate an evaluation at the OUHSC Child Study Center, other physician referrals, a Supplemental Security Income application and her referral to other DHS services. She also drove the mother and child to the appointment at the CSC and accompanied them so she could help them with the paperwork, and waiting for testing. She also helped the mother understand her child's disabilities, helped her to enroll her child in the school for the blind and later helped him integrate back into the community.

3. A county coordinator (navigator) helped a family of a 14 year old child with Muscular Dystrophy devise a system that enabled him to bathe utilizing a portable bath tub. The project cost $400 provided by the Ministerial Alliance and a pharmacy discount.

4. A county coordinator (navigator) helped several families who have had issues with their children's school such as absences and tardiness where she is able to act as a mediator between schools and parents.

Capacity Building:

The program has been the impetus for several additional initiatives including the training of PCPs to use evidence based developmental screening which received additional funding from the Centers for Disease Control and Prevention and the development of a web portal that has enhanced communication between PCPs and Sooner Start the state early intervention regarding children from PCPs who are referred to the earlier intervention program in collaboration with OHCA and supported by a grant from the Commonwealth Fund. The county coordinator (navigator) in Canadian county and the regional coordinator also helped facilitate Canadian county's attainment of a Health Access Network status. Over the years the program has provided a 2-5 times the return in additional funding for the cost of the programs.

As specific capacity building examples:

1. A county coordinator (navigator) recruited a counselor from a neighboring county behavioral health program to provide sessions at school in the county once a week. The coalition was able to eventually to expand the county counseling services to

five days a week supported by fee for services and a grant.

2. A county coordinator (navigator) arranged through the Oklahoma Dental Foundation to have the Mobile Dental Van come to all 4 of the schools in her county. From the dental van visits, the Oklahoma Dental Foundation provided in excess of $100,000.00 worth of dental work to children in that county.

3. Based on a needs assessment of a county, it was evident that in that county they had no regularly occurring respite programs for children with special needs despite the fact that some funds were available for those services. The county coalition was able to design a respite program to address this need. The program provides a free evening of respite once per month for families in the county in partnership with a local church. It serves both children with special needs & their siblings ages 6 months to 12 years and provides a trained 1 on 1 volunteer for each child to support both individual and peer to peer play time as well as a volunteer support team to offer breaks, provide assistance, and ensure safety. As of July 1, 2012 the program has served 49 children from 12 families and has recruited and trained 40 community volunteers with growth in attendance each month. The program has been funded through community support and private donations.

DISCUSSION

The requirements of children with special needs are frequently varied and complex. Addressing them requires multiple service domains including health, education, human services and mental health. Programs focusing on single conditions or domains of service fall short of meeting the families' needs. Directives that are generated at a state and national basis while helping to support and stimulate programs are not able to easily adjust to the unique needs individual communities.

The unique aspect of the Sooner SUCCESS program is that it takes a complex adaptive systems approach[5,6] allowing for unique local solutions to problems. It has put in place the organizational structure for local communities to address their needs in their own unique ways in a coordinated fashion and it provides ongoing feedback to the communities to help them in their activities and decisions.

The assumption is that the problems of this nature are not easily solved and that rather than trying to come up with initiatives to address the problems with major interventions, it will be more effective in the long run to have in place an organizational structure that provides gradual incremental small changes generated mostly at the community level. The initial results of this project over the past 10 years suggest that the desired results are slowly evolving.

REFERENCES

1. Oasis. Statewide Information and referral for Oklahomans with Special Needs. 2010 September 2010 [cited May 10, 20011]; Available from: http://oasis.ouhsc.edu/.
2. Dawson, G., et al., Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, 2010. 125(1): p. e17-23.
3. Perrin, J., et al., A family-centered, community-based system of services for children and youth with special health care needs. *Arch Pediatr Adolesc Med*, 2007. 161(10): p. 933-6.
4. Antonelli, R. and Antonelli DM, Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice. . *Pediatrics*, 2004. 113(5 Suppl): p. 1522-8.
5. Matlow, A., et al., How can the principles of complexity science be applied to improve the coordination of care for complex pediatric patients? Qual Saf Health Care, 2006. 15: p. 85-88.
6. Plsek, P. and Wilson T, Complexity science: Complexity, leadership, and management in healthcare organisations. *British Medical Journal*, 2001. 323: p. 746–9.

Ages and years Waiting

Ages	Less than 1 year	1 to 2 years	2 to 3 years	3 to 4 years	4 to 5 years	5 to 6 years	over 6 years	Total
0-3	96	64	29	9	-	-	-	198
4 -6	63	87	54	91	74	60	17	446
7 - 18	303	253	191	322	333	375	822	2,599
19 -21	68	102	82	119	118	113	218	820
22 - 35	90	130	122	167	262	296	877	1,944
36 - 55	71	107	60	71	90	104	292	795
56 - 64	13	26	8	15	25	30	76	193
65 - 74	4	7	1	3	2	8	30	55
75	-	-	-	1	-	-	1	2
76	-	-	-	-	1	-	-	1
83	-	-	-	-	1	1	-	2
	708	776	547	798	906	987	2,333	7,055

253 Aging Oklahomans Waiting

Services Provided to those on Request List by Age

	AL	CIE	ADC	FSS	GH	Medicaid	TEFRA	SNAP	Obra	SW	SSI	No services
0-3	-	-	-	96	-	150	22	74	-	-	101	25
4 -6	-	-	-	178	-	300	37	138	-	-	207	97
7 - 18	-	3	-	822	-	1,737	144	759	1	5	1,318	637
19 -21	1	28	-	-	6	510	-	251	1	29	425	209
22 - 35	4	123	1	-	43	1,181	-	705	15	175	868	512
36 - 55	16	47	3	-	35	489	-	242	31	98	250	205
56 - 64	10	6	-	-	12	120	-	38	21	24	47	47
65 - 74	4	4	-	-	6	35	-	7	9	7	13	13
75	-	-	-	-	-	2	-	1	-	-	1	-
76	-	-	-	-	-	1	-	1	-	-	-	-
83	-	-	-	-	-	1	-	1	-	-	1	1
	35	211	4	1,096	102	4,526	203	2,217	78	338	3,231	1,746

Key Services Received

- AL - Assisted Living
- CIE - Community Integrated Employment
- ADC - Adult Day Care
- FSS (Family Support Subsidy) - $250 monthly
- GH - Group Home
- Medicaid - Oklahoma SoonerCare
- TEFRA - SoonerCare for children w/severe medical needs
- SNAP - Food Assistance Program (food stamps)
- Obra (See explanation on left)
- SW - Shelter Workshop
- SSI - Supplemental Security Income

The "Services Provided" information is gathered by OKDHS. OKDHS uses their existing system along with other systems and reconcile the service recipients names with the waiting list names. It is a current as available to OKDHS.

**Obra - Omnibus Budget Reconciliation Act (1987) which created Preadmission Screening and Resident Review (PASRR) for people with or suspected of having mental illness, mental retardation and related conditions who are seeking admission to or are residents of nursing facilities. It is a Preadmission Screening evaluation because the person either sought admission to a nursing home or already was a resident of a nursing home. It does not mean the person was admitted to the NF necessarily, although they may have been IF they met the need for NF services.

As of May Dec. 9, 2013
6,998 WAITING

Waiting In Oklahoma
www.okwaitinglist.org

Key Resident Type

- Res Cen - NORC & SORC
- Custody - in state custody
- OH/PH/RH - Own Home/Parents Home/Relative Home
- GH - Group Home
- FC - Foster Care
- Inc - Incarcerated
- ICF/MHF/AL/NF - ICF/MR type home
- UNK - Unknown

As of Sept. 30, 2013
6,268 live in family, parent's or own home

Request List by Residence Type and Age

Ages	Res Cen	Custody	OH / PH / RH	GH	FC	Inc	ICF/ MHF/ AL/NF	UNK
0-3	-	7	190	-	-	-	-	1
4-6	-	15	421	-	3	-	2	5
7-18	1	148	2,370	4	16	-	15	45
19-21	1	29	748	3	3	2	7	27
22-35	3	7	1,730	40	4	9	61	90
36-55	3	-	645	29	1	12	73	32
56-64	-	-	128	16	-	2	36	11
65-74	-	-	31	7	-	-	17	-
75	-	-	2	-	-	-	-	-
76	-	-	1	-	-	-	-	-
83	-	-	2	-	-	-	-	-
	8	206	6,268	99	27	25	211	211

School Age - After school and summer care needed

After high school - working parents

Aging individuals - who's supporting them now?

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Distributed by Wanda Felty parent & Coordinator of The Waiting List Meeting wfelty@okphotopros.com
12/12/2013 Waiting List Meeting - Tulsa

Wednesday, April 9th, 2014 – OGR Subcommittee hearing:

"Examining Ways the SSA Can Improve the Disability Review Process"

Ms. Jennifer Lockhart, State Director, Sooner SUCCESS,

The University of Oklahoma Health Sciences Center

Jennifer Shaw Lockhart

As State Director for Sooner SUCCESS and Co-principle Investigator with Dr. Mark Wolraich, Jennifer continues towards advancing an INCLUSIVE comprehensive, unified system of health, social, and educational services for Oklahoma children on both the local and state level. To assure seamless navigation, partnerships and networking on multiple cross agency projects, committees and taskforces are needed. As the Director, Jennifer has participated in several committees including, but not limited to, ABCD3 State Team, RESPECT (Rethinking Special Education) taskforce committees, Understanding the Structure committee, High School Transition committee, Compliance and Legal Issues committee at the request of Rep. Jason Nelson; Department of Humans Services Inclusive Childcare Taskforce, SMART START Special Populations Task force, The Oklahoma Children's Hospital Patient's Experience Strategic Team, Home Visitation Workgroup at the request of Rep. Mike McCullough, The Sickle Cell Anemia work group at the request of Rep. Anastasia Pittman, Parent Pro Home Visitation Sustainability Committee at the request of Jane Solvisky Ph.D. and IMPaCT Quality Improvement committee at the request of Dr. James Mold. The director co-chairs the Pediatric Acquired Brain Injury (PABI) state integration team, the Oklahoma Antibullying Collaborative and is also a member of the OKPRS Data workgroup. She served as a panel member for the Brain+Child conference hosted by Integris Medical Center. Meetings are monthly or bi-monthly, unless specified. She also works with family advocates within special populations seeking legislative system solutions and is currently working with Oklahoman Julie Lackey in an effort to bring higher education options for individuals with disabilities to the state. On an individual case, the director continues to handle more high intensity care coordination cases that potentially may lead to due process and has also been brought in as a consult for community integration for children in care with profound behavioral or developmental challenges requiring high confidentiality.

The director provides oversight and direction to day-to-day operations including administration, personnel issues, contract monitoring, program and project fidelity, website and IT infrastructure, marketing-branding, bi-monthly staffing, IRB approval, HIPAA FERPA compliance, and budgets. Further she has continued in facilitation with partner collaborations for the Family Resource Center in the Children's Hospital.

Jennifer studied early childhood development and behavioral studies at Oklahoma City University and Family Studies at Southern Nazarene University and would like to pursue her Ph.D. in public Health when her youngest son graduates from High School in a few years. The beginning of her career began at Dale Rogers Training Center over 20 years ago, an employment and work solution center for individuals with disabilities. Later Jennifer was a teacher in Oklahoma City, and worked at other human service organizations like Easter Seals Oklahoma and Oklahoma County Court Appointed Special Advocates. She is a former CASA and is also in the process of volunteer guardianship of an individual transition into the community from an Oklahoma State Institution currently closing.

Name: Jennifer Lockhart

1. Please list any federal grants or contracts (including subgrants or subcontracts) you have

received since October 1, 2011. Include the source and amount of each grant or contract.

Oklahoma State Department of Education, FY11 $64,758.00 FY12 $64,758 FY13 $54,018

Oklahoma State Department of Human Services- Family Support Title V, FY11 $177,047, FY12 $177,047, FY13 $297,035 FY14 $397,035

Oklahoma State Department of Human Services- Developmental Disabilities Services Division- FY13 $62,093 FY14 $62,300

Oklahoma Developmental Disability Council FY11 $52,476, FY12 $60,822 FY13 $58,381 FY14 $27,496

Oklahoma Health Care Authority FY11 $259,905 FY12 $295,520 FY13 $291,463

Oklahoma State Legislature Match FY11 $259,935 FY12 $296,213 FY13 $291,463

2. Please list any entity you are testifying on behalf of and briefly describe your relationship

with these entities. Sooner SUCCESS: Individuals with disabilities specifically children and youth with special needs. Director, Sooner SUCCESS.

3. Please list any federal grants or contracts (including subgrants or subcontracts) received

since October 1, 2010, by t he entity(ies)

you listed above. Include the source and amount of each grant or contract.

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I certify that the above information is true and correct.

Signature: Jennifer S Lockhart Date: 4·7·2014