

Palmetto Coordinated System of Care

Evaluation Brief: Key Stakeholder Interviews

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EVALUATION BACKGROUND AND PURPOSE

The first statewide system of care efforts were established through a multi-agency collaboration led by SC Department of Mental Health (DMH) through a Substance Abuse and Mental Health Services Administration (SAMHSA) planning grant in 2011. In 2014, SC Department of Health and Human Services (DHHS) received a SAMHSA expansion grant to begin implementation of a statewide system of care, known as the Palmetto Coordinated System of Care (PCSC). The purpose of the PCSC is to build a system of care (SOC) and implement it statewide to serve children and youth who have significant behavioral health challenges and who are in or most at risk of out-of-home placement.

In November 2015, the South Carolina Department of Health and Human Services (SC DHHS) contracted with the Core for Applied Research and Evaluation (CARE) to conduct a process and outcome evaluation of PCSC. The goal of this evaluation is to understand program implementation, as well as to determine progress towards its mission to provide services to children and families and enable them to achieve safe, healthy, and functional lives as successful, responsible, productive citizens. The initial evaluation activity included in this report is a set of 14 in-depth interviews designed to provide data regarding the operations and benefits of PCSC to program leadership, key stakeholders, and the children and families it is designed to serve.

EVALUATION METHODS

The University of South Carolina Institutional Review Board approved this study. Based on recommendations from the PCSC Program Director, a list of suggested interview candidates was developed including key stakeholders and partners. This list was utilized to recruit participants for in-depth interviews during January, February, and March 2016. Additionally, we asked interviewees to identify any further stakeholders they thought may be helpful at the end of each interview. We conducted 14 interviews via telephone and a variety of roles and perspectives were represented including agency leaders and staff members, nonprofit agency staff, and parents.

A semi-structured interview guide was designed to assess several aspects of PCSC including: the level of stakeholder engagement, facilitators and barriers of implementation, adoption and adherence to the PCSC work plan, the reach of PCSC, and the context in which implementation of PCSC is occurring.

Sample questions included, *“Think back to before the PCSC program began... what changes to the behavioral health system have you observed?, How clear are you on your role in implementing PCSC...including timeline, strategies, and activities?”* and *“What activities and strategies to implement PCSC seem to be working well? What strategies are not working as well?”* The complete interview guide is included in the appendices (Appendix I); a slightly adapted version of the interview guide was created for families and peer support leaders (Appendix II). Interviews were tape recorded and detailed notes were assembled from the recordings. Recordings and any paper notes were stored in locked file

cabinets at the CARE offices at the University of South Carolina. Audio-recordings were erased after analysis.

An inductive approach was used to analyze interview data, which allows themes to emerge from data. A qualitative analysis software (NVIVO v. 10) was used to organize the analysis. The evaluation team used consensus coding, wherein theme definitions and meanings were decided upon through an agreement process. Data were reviewed until saturation was reached (no new themes or ideas emerge from the data) and recurring themes were identified.

SUMMARY OF FINDINGS

Facilitators of Implementation

Buy In Established Among Key Stakeholders: Clear Communication of PCSC Vision Promotes Implementation

Efforts from PCSC leadership to communicate the overall vision and purpose of the project have been successful. The majority of interview participants agreed that a variety of stakeholders involved including high-level leadership, families, and staff, are aware of the overall PCSC vision, which helped develop buy-in for the program. High-level leadership, including the Governor's office and state agency directors, were bought in from the beginning of the project and prioritized PCSC. In part, this was facilitated by the establishment of the PCSC Leadership Team, which includes representation from these state agency leaders.

A key piece of PCSC's operational structure includes this Leadership Team, as well as 12 additional workgroups assigned tasks crucial to the PCSC project. Workgroups allow a space for topic-based problem solving and discussion. This allows for stakeholders to support PCSC, but also requires a level of maintenance and commitment. Some stakeholders believe that the structure provided by the workgroups has been effective and facilitated communication; however, others feel communication from PCSC leadership to the workgroups could be improved. The PCSC project has held more than 170 workgroup meetings in two years.

In addition, family buy-in and involvement was also seen as a facilitator of PCSC implementation. While some stakeholders believed more work could be done to get families to buy in, most stakeholders felt that family buy-in was facilitated by a cultural shift in working *with* families, not *on* families. Family members are integrated across several of the workgroups to ensure that activities remain family focused. One person described the importance of including family members in PCSC workgroups to ensure that family voices were heard *"In a broader perspective, you have our leadership team and there are three family members that sit on it. The family members are able to describe what is actually happening on the ground level and what they have experienced while working with the agencies. They are on equal footing with the agency directors and have the same weight of vote. This keeps what we are doing, authentic. The families keep this process real."*

Strong Working Relationships Built by PCSC Leadership Support Implementation

Program leadership has been effective at building working relationships with key stakeholders, as well as maintaining those relationships through the continued involvement from partners. PCSC Project Director Gwynne Goodlett's leadership was described as *"team-focused"* and *"positive"*. One interview participant praised Gwynne's approach to facilitating relationships and buy-in through conducting surveys to solicit input, as well as giving presentations about PCSC in the community.

SC Continuum of Care's WrapAround Program an 'Early Win' for PCSC

The WrapAround program and staff were seen as facilitators of implementing the PCSC program, as well. The WrapAround structure was also seen as a facilitator, as the structure gives a concrete example of the overall essence and values of PCSC, as it is family-driven and a coordinated, comprehensive system of care. The WrapAround staff were described as professional and good ambassadors of the program. They were able to model the values of the program through strengths-based language and were inclusive of the families during the process. This helped to influence how other agencies treated families enrolled in the WrapAround program and even outside of the WrapAround program, helping to influence a cultural shift from working *with* families, not *on* them. For example, one person described, *"The fact that we do have the ability to provide crisis management in the homes within a high intensity case is very effective...The whole goal of Wraparound is to decrease the use of formal services and increase the use of informal services so that when we do leave, families still have that same level of support. These things are what have been working and what I really like."*

Successes of PCSC

PCSC Incited Systems Level Change

Due to the implementation of PCSC and the resulting strengthened partnerships, stakeholders describe that PCSC has produced the high level, systems changes it sought out to accomplish. Observed systems-level changes included more coordination and communication between agencies and coordination of services. An interview participant described the change, from their perspective...*"The state agencies are communicating much more effectively and more frequently. There have been concrete steps taken to address issues that have caused kids to fall between the cracks. Solutions to address the needs of the kids have been created much more efficiently...Ideally, kids that have significant behavioral health issues will be able to seek help within their homes and will not have to resort to trips to the ER and that would be an outcome that would be achievable in every county in the state. The important factor is that state agencies are involved in providing these services... In the past, the coordination was extremely disjointed. We have improved the communication gaps between all of these state agency players."* Stakeholders agreed that one way these systems-level changes started occurring was because high-level leadership made it a priority, which was a successful event in itself.

Successful implementation of WrapAround at SC CoC involved a cultural shift that made services family-driven and empowered families to have an active voice in decision making. For example, WrapAround families now have a single plan of care. One interview participant stated, *"The direction that we're going in, where children will be able to stay in the community instead of going to residential setting....Staying in the home is of vital importance and the family receives the services and supports needed. It's happening because of PCSC...We know that children do better with their families in the home in their communities. I think we are on a great track to make some significant changes."* In addition, the strengths-based approach also illustrates this shift as it builds assets around the family and reflects the changing attitudes around mental illness. As a result, stakeholders report that more families

are transitioning out of intensive care and children's lives are improving. Also, there is no longer a waiting list for services at the CoC and access to services has been improved.

Improved Partnerships

Improved partnerships were also noted as a success of the PCSC project thus far. Partnerships between state agencies, nonprofit organizations, and providers were mentioned. An interview participant described, *"There has been a lot of outreach to service providers and families, to peers and to other groups that has elevated the need for having a better coordinated system of care...Getting the top agencies all communicating and working together on a regular basis has been a huge success."* As an example of improved partnerships, Medicaid has opened up billing codes so that PCSC meeting times could be billed for, as the PCSC project is dependent upon partners participating in workgroup meetings. As a key illustration of enhanced partnerships, interview participants described the *Building Bridges Initiative*. The *Building Bridges Initiative* has been a successful outreach project to get Psychiatric Residential Treatment Facility Services (PRTF) providers on board with the PCSC project. While continued work is needed to bring PRTF partners to the table and build these relationships, the initial outreach has been successful.

Barriers to Implementation

Several barriers to implementation were identified by PCSC stakeholders. Interview participants described the need to engage additional stakeholders, continue to develop communication and outreach strategies, and address the stigma around mental health. Turnover in WrapAround staff, changes in DHHS leadership, and fatigue among PCSC workgroup members were described as issues. Finally, the overall lack of mental health resources in the state was discussed as it impedes progress.

Engagement of Additional Stakeholders Needed

Although buy-in was described as a facilitator to implementation, it was also mentioned as a barrier to implementation of PCSC. Interview participants described that state agencies including the DJJ, DSS, the Department of Education, and school systems are missing from the table and still need to be engaged. External factors at these agencies may be taking their attention away to more pertinent issues for them; however, stakeholders agreed that not having these partners at the table was a hindrance. For example, one person remarked on the absence of one of these key partners, *“They [Department of Education] are a needed partner that is glaringly absent.”* Furthermore, PCSC also represents a cultural shift in treatment that some agencies may not be fully bought into yet. Thus, communication and outreach may facilitate addressing this issue as the complexity of PCSC and program activities may have contributed to these partners not being at the table. The complexity of the project may have attributed to unclear communication and lack of these partners being engaged in the program.

Persistent Stigma of Mental Health

The persistent stigma surrounding mental illness was also described as a barrier to PCSC implementation. Stigma may prevent families from seeking treatment or even accepting a diagnosis. Stigma and related issues affect agencies, families, schools, healthcare providers, community-based organizations, and schools. Furthermore, teachers and administrators at schools, healthcare providers, social workers, and those working with families in other community-based settings may not want to discuss mental illness with parents because of stigma. Some stakeholders reported that stigma was especially problematic in rural areas and plays a significant role in parents not seeking a diagnosis or treatment. For example, one interview participant talked about the challenge of addressing stigma and mental health, *“It’s educating in a state where there’s still is so much stigma around mental health conditions. You can’t will yourself to come out of a state of depression any more than willing your blood sugar up or down...So we have to convince parents, teachers, any one that these are truly illnesses...we have people that are more comfortable with talking about loved ones in jail than loved ones with mental illness.”*

In addition to the overall stigma of mental health, issues specific to the state social service agency were described as a barrier to partnering with DSS service providers and families. For example, one participant explained, *“We [DSS service providers and DSS-involved families] are not getting represented on the same level...and I think it has to do with the stigma attached to these families...these families have the exact same issues, their needs have just been unmet for so long, some really disastrous things started to happen...so if we’re talking about coordinating care...my one large complaint is that child welfare and juvenile justice do not have their families represented like the other families are....we’re*

trying to figure out how to close all the gaps...so you really don't want to listen to the families that fell through every gap you had?"

Changes in Delivery of Care Resulted in Wraparound Staff Turnover

When WrapAround was first implemented, it created a broad cultural shift in the way care was delivered. There was resistance among staff to this change, as it required staff to offer availability for after-hours meetings with families and sharing of case documents with families. In some cases, these changes resulted in staff turnover. However, turnover in WrapAround staff has subsided and is not considered a current problem.

Leadership Changes at SC DHHS, Stakeholder Fatigue Impact Implementation Momentum

Although the initial leadership exhibited by DHHS facilitated early implementation of PCSC, stakeholders described implementation slowed down after then Director Tony Keck left the agency in November, 2014. One interview participant said, *"The leadership at DHHS changed and the momentum left."*

Also, participants expressed that project momentum has slowed because of fatigue among PCSC workgroup members and key stakeholders. Due to the complex nature of PCSC and its efforts to change systems-level factors, communicating the tangible activities of PCSC has been challenging, which has resulted in the fatigue. For example, many stakeholders expressed that they could define the purpose of the project overall, but could not explain the specific activities, work plan, or strategic plan.

Contract Procurement Process a Hindrance

Another barrier to PCSC implementation was the process of contract procurement. A contract to implement PCSC outreach activities was awarded to a large, national nonprofit entity. Some PCSC partners who represented smaller organizations in the state felt the larger nonprofit entity did not have the structure, manpower, and connections that they had established in SC. They felt this process was unfair and it harmed relationships with these organizations. Also, coordinating services across state agencies has reduced costs. Although this is a positive, agencies that were sharing costs and had to come to an agreement about how to split the shared, reduced funding. This may have been a barrier to implementation at first, but it does not appear to be a current problem.

Mental Health Infrastructure Not Sufficient to Support PCSC

A lack of mental health infrastructure, including too few qualified providers and preventive services (such as planned respite and a mobile crisis unit), have been issues for PCSC implementation. This is especially problematic in the rural areas that have even fewer providers and longer travel distances. Other resource issues include Medicaid and insurance billing and restrictions on preventative care and crisis management.

In addition, families face barriers such as long waiting periods to see providers, lack of available appointments scheduled after work and school hours, and transportation. This lack of access to preventative treatments leads to more crisis situations, including extended hospitalizations, admittance into long-term treatment facilities, school behavioral problems, DSS involvement, or law enforcement involvement (including incarceration).

Providers committing Medicaid fraud during the last couple of years has drained funding and affected the number of providers available. Also contributing to the resource deficit is the new process that allows families to put children in long-term care without agency involvement. Previously, in order to access behavioral health services, families were required to go through a state agency that would put up the 30% match for federal Medicaid to pay the 70% of costs. However, in July 2014, this changed when Medicaid representatives removed the requirement that state agencies be involved in accessing behavioral health services. Parents could access services directly, including psychiatric residential treatment facilities (PRTF), without any state agency knowing they were accessing services. This process empowered parents, but it left state agencies completely out of the process. State agency staff may not know that one of their current families had placed a child in PRTF, leaving them out of the communication loop. Furthermore, state agency staff members were no longer asked to weigh in on PRTF placement decisions, where it may not necessarily be recommended to place the child in a PRTF. In other words, state agency staff may have recommended community-based services or other alternatives than PRTF placement if they were a part of the process. This left parents accessing the more costly PRTF services in lieu of community-based services that they may not have even known existed, resulting in further draining funding. Currently, Medicaid is considering a more robust discharge process to ensure children aren't staying in PRTFs unnecessarily. However, this process has drained already sparse resources and led to more restrictions on getting desperately-needed services. One person expressed their perspective on opening PRTFs to parents....*"This isn't a cost-savings program....You have an issue of people accessing very expensive services that they may not need to be accessing."*

Exacerbating this problem is the fact that other states are placing children under their state's care in SC PRTF providers' care. SC PRTF providers receive less money per child for in state children as compared to out of state. Therefore, PRTF providers are deterred from taking SC children and are accepting out-of-state children before SC children. This results in an even smaller number of slots for SC children. Additional issues with Medicaid prior authorization exist as well. Program requirements for WrapAround services have been a barrier to accessing services in a timely manner. When these barriers prevent families from accessing care, prevention of further crisis situations is jeopardized. WrapAround is not recognized by Medicaid as a care management entity; therefore, prior authorization is required to access services. This has resulted in increased wait times for children that need care. For example, WrapAround staff working with DJJ-involved children need to be able to assure judges in court that children will have access to services immediately, so that they can get the services they need (rather than being incarcerated at DJJ). Medicaid prior authorization requirements prevent WrapAround staff from being able to guarantee this to a judge, and judges are often forced to put the children in the care of DJJ and not in the care of WrapAround staff. DJJ-involved children may not be getting the treatment they need, further exacerbating the mental health crisis. One person explained the great risk of this predicament, *"My only experience with DJJ is that the children come out worse than when they went in."*

Areas for Improvement

Areas for improvement include additional outreach, communication, and relationship building, development of an updated strategic plan, addressing lack of resources and billing issues, and improving data systems.

Continue Communications, Outreach, and Relationship Building Efforts to Strengthen Buy-In for PCSC and Engage All Partners

Efforts to maintain buy-in among partners are needed, as well as the development of relationships among less-engaged partners. To keep current partners involved and to recruit new partners, communication and outreach efforts should continue with a focus on PCSC values. Projects, such as the *Building Bridges Initiative*, need to continue to address resistance to change among those that may not have fully accepted the PCSC principles (for example, PRTF providers). Recruiting DJJ, DSS agency staff and DSS families, the Department of Education, and school system representatives as partners is also an area for future improvement. Finally, relationships with partners that were damaged during the contract procurement process need to be addressed. Moving forward, it is suggested that funding streams and the contract procurement process are as transparent as possible.

The continued use of communication and outreach strategies to address the stigma associated with mental health issues is needed, as well. These efforts could include working with families, school personnel, healthcare providers, social workers, and family service agencies. One interview participant noted their uncertainty regarding PCSC's communications strategies...*"How do we let everyone know this is happening? Are families going to be able to know there are services? Are providers going to know about the services?"* Also, a key component to consider is reducing the stigma surrounding work with DSS families. Given the clear role of communications and outreach to the success of PCSC, the Communications Workgroup's role may need to be refined to promote future success.

Develop an Updated Strategic Work Plan

A comprehensive strategic work plan to communicate concrete program activities is needed. Stakeholders expressed that they would like to have a "state of the state" meeting, where a strategic plan and next steps would be discussed. Currently, there is a lack of knowledge among some stakeholders about strategies. For example one person noted that they were not familiar with all of the PCSC strategies...*"I don't know any strategies that aren't going well because I don't know all of the strategies."* Important updates, such as the Medicaid Waiver (1915c waiver) application process, the specific implications for PCSC, and newly-acquired funding for a mobile crisis unit, need to be communicated. Also, stakeholders would like more clarity on their roles within the PCSC project.

Also, work to clearly define and communicate PCSC's target population for project activities is needed. Many stakeholders lack clarity on the target population. Stakeholders referred to the 'triangle of services', suggesting that PCSC initially targeted children with the most needs (top tier, 2-5%). Without a clear strategic plan, stakeholders were unclear about who the target audience of PCSC is and will continue to be in the future. For example, stakeholders wondered if PCSC will target children needing fewer mental health services (second tier, 6-15%; bottom 80%). It is also unclear to stakeholders if PCSC

is designed to engage with youth with personality disorders or very young children (under 5), as it appears that thus far, WrapAround is not engaging with these groups effectively. A stakeholder looking for clarification explained, *“They have cross over, but they’re not looking the breadth of families. If you’re just working on the top of the triangle, say that.”*

Furthermore, clarification is needed on what population the proposed mobile crisis unit would be serving, what services will be available to prevent youth discharged from the WrapAround program from cycling back in, and lastly, what activities will be put into place to prevent second tier children from cycling into the first tier and requiring intensive services for the first time.

Address Continued Needs for Infrastructure Development

Another area for improvement is infrastructure development. As described earlier, the mental health care system across the state lacks resources. As a result, it is difficult for PCSC project to address all areas of need. However, some issues including the need for a mobile crisis unit, planned respite care, and Medicaid prior authorizations, may mitigate some barriers (especially barriers to preventative treatments). Rural areas may need special consideration, as the effects of resource-poor areas are compounded by transportation issues. Some stakeholders from rural areas reported some success with tackling transportation issues.

Need For Integrated Data Systems

The ability to share data across agencies is another area of infrastructure improvement for PCSC to consider. This includes capturing metrics such as case closures, police encounters, and incarcerations. Additionally, data is needed on school behavioral issues.

APPENDICES

Appendix I: PCSC Interview Guide 2016

I am with the Core for Applied Research and Evaluation at U.S.C., which is doing the evaluation of the Palmetto Coordinated System of Care (PCSC). As part of the evaluation, I would like to ask you a series of questions about your experience with PCSC. The purpose of these interviews is to identify the facilitators and barriers of PCSC project implementation, to document how close the work plan is being followed, and the context in which it's occurring. If you agree to participate, I will be asking questions about your experiences working with PCSC and with the behavioral health system.

Some questions may apply to you in your role on the project and others may not. We can skip any question you'd prefer not to answer or you feel does not apply to you. Is it O.K. for me to take notes on my computer and record your answers on a digital recorder as we go along? Also, I will check in with you to make sure I understand your answer correctly, O.K.?

The interview will likely take less than one hour. You can stop the interview at any time. All your responses to the questions will be kept confidential, so no one will be able to link your answers to you. I collect a group's responses and look for common themes then provide feedback in summary form. Is it alright with you that we precede with the interview?

1. How have you been involved with PCSC?

Probe: What PCSC activities have you participated in?

2. Please tell me a little bit about the purpose of PCSC (as you understand it).

Probe: How well organized is PCSC to accomplish that purpose?

3. Think back to before the PCSC program began... what changes to the children's behavioral health system have you observed?

Probe: Have those changes occurred because of PCSC?

4. How clear are you on your role in implementing PCSC...including timeline, strategies, and activities?

Probe: Familiarity with PCSC work plan?

Probe: If yes, how much input did you have on deciding these details (timeline, activities, and strategies)? If no, how could it be clarified?

5. What activities and strategies to implement PCSC seem to be working well? What strategies are not working as well?

6. What are the biggest challenges of the PCSC, so far?

Probe: When you think about PCSC, do you have concerns about anything? If so, what are they?

7. What are the biggest successes of PCSC, so far?

8. Are there agencies and/or particular people that have provided leadership to PCSC thus far?

Probe: If so, who are they and what have they done to lead the process? If not, where is more leadership needed?

Probe: Changes in DHHS leadership?

9. PCSC involves many moving parts and fundamental changes, which involves a lot of buy-in from various partners and agencies. How 'bought in' do you think that everyone is to the PCSC ideas and changes?

Probe: If not, what changes have the least amount of buy-in and why? How do you think buy-in can be achieved?

10. Imagine the ideal behavioral health system for children in South Carolina....tell me what that system looks like in your head.

Probe: Are we on the right track to develop that ideal system?

Probe: Do you think that it is realistic to think that these changes will be accomplished by the end of the SAMSHA grant?

11. What else do you think that I should know about PCSC that I haven't asked you about?

12. Who else do you think that I should talk to?

Appendix II: PCSC Interview Guide for Families and Peer Leaders

I am with the Core for Applied Research and Evaluation at U.S.C., which is doing the evaluation of the Palmetto Coordinated System of Care (PCSC). As part of the evaluation, I would like to ask you a series of questions about your experience with PCSC. The purpose of these interviews is to identify the facilitators and barriers of PCSC project implementation, to document how close the work plan is being followed, and the context in which it's occurring. If you agree to participate, I will be asking questions about your experiences working with PCSC and with the behavioral health system.

Some questions may apply to you in your role on the project and others may not. We can skip any question you'd prefer not to answer or you feel does not apply to you. Is it O.K. for me to take notes on my computer and record your answers on a digital recorder as we go along? Also, I will check in with you to make sure I understand your answer correctly, O.K.?

The interview will likely take less than one hour. You can stop the interview at any time. All your responses to the questions will be kept confidential, so no one will be able to link your answers to you. I collect a group's responses and look for common themes then provide feedback in summary form. Is it alright with you that we precede with the interview?

1. How have you been involved with PCSC?
Probe: What PCSC activities have you participated in?
2. Please tell me a little bit about the purpose of PCSC (as you understand it).
Probe: How well organized is PCSC to accomplish that purpose?
3. Why did you decide to become involved with PCSC?
4. Think back to before the PCSC program began... what changes to the behavioral health system have you observed?
Probe: How have these changes affected your care or your child/ren's care?

Probe: Have those changes occurred because of PCSC?
5. How clear are you on your role in implementing PCSC...including timeline, strategies, and activities?
Probe: Familiarity with PCSC work plan?

Probe: If yes, how much input did you have on deciding these details (timeline, activities, and strategies)? If no, how could it be clarified?
6. What activities and strategies to implement PCSC seem to be working well? What strategies are not working as well?
7. What are the biggest challenges of the PCSC, so far?
Probe: When you think about PCSC, do you have concerns about anything? If so, what are they?
8. What are the biggest successes of PCSC, so far?
9. Are there agencies and/or particular people that have provided leadership to PCSC thus far?

Probe: If so, who are they and what have they done to lead the process? If not, where is more leadership needed?

Probe: Changes in DHHS leadership?

10. PCSC involves many moving parts and fundamental changes, which involves a lot of buy-in from various partners and agencies. How 'bought in' do you think that everyone is to the PCSC ideas and changes?

Probe: If not, what changes have the least amount of buy-in and why? How do you think buy-in can be achieved?

11. Imagine the ideal behavioral health system for you or your child/rentell me what that system looks like in your head.

Probe: Are we on the right track to develop that ideal system?

Probe: Do you think that it is realistic to think that these changes will be accomplished by the end of the SAMSHA grant?

12. What else do you think that I should know about PCSC that I haven't asked you about?

13. Who else do you think that I should talk to?