

Interim Report: Respite Care Services Workgroup

Submitted April 2011

Introduction, Background and Charge

In February, 2010, The Commissioners' Committee on Cross-Systems Youth asked its Senior Staff and Family & Youth Partners to form a study and work group to identify issues related to Respite Care with a cross-system focus. Through multiple vehicles and venues, including personally attended regional hearings across the state, the cross-systems Commissioners heard about a range of issues associated with the supply, demand, access to, understanding, availability, accessibility, affordability, and effectiveness of local respite care services. Respite care issues to be studied included access, planned and emergency respite services. The group was also asked to recommend remedial strategies and outline a plan moving forward. By way of this interim report, the Respite Care Services Workgroup conveys its findings to date and suggests strategic directions for the Senior Staff and Family & Youth Partners and Commissioners' Committee's consideration.

Group Membership Representatives of the Following State Agencies, Organizations and Systems

- Council on Children and Families (CCF)
- Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC)
- Families Together in NYS (FTNYS)
- Office of Children and Family Services (OCFS)
- Department of Health (DOH)
- Office of Mental Health (OMH)
- Office for People With Developmental Disabilities (OPWDD)

Findings

- Planned respite care is lacking in NYS, especially for cross-systems youth.
- No cross-systems serving programs that came to our attention have adequate emergency and crisis respite capabilities.
- There is no consistent definition of respite care, policy, procedure, or practices across state agencies. While common themes for defining and providing respite care services exist, there are some regulatory differences among the state agencies.
- Regulations do not adequately differentiate between types of respite services, (i.e. planned, emergency, crisis, etc.) across the child serving systems.
- Cross-system coordination is inconsistent on the county level; each child-serving system has its own referral pathways, triage efforts, and contracting patterns.

- For youth enrolled in NYS sponsored programs (OMH, OPWDD, OCFS), planned respite frequently takes several months to establish as part of a treatment plan and is barely adequate.
- Emergency respite availability is virtually non-existent for youth not currently enrolled in OMH, OPWDD, OCFS, or DOH programs, in some cases; eligibility is limited to waiver-enrollment.
- Local respite planning and response varies widely for cross-system youth. These variances have had none to relatively little state inquiry or intervention and are driven by local conditions including but not limited to geography, the political and economic landscape, creativity of key community staff, issues of supply and demand, cultural traditions, etc.
- The lack of crisis respite results in children being picked up by law enforcement or presenting in emergency rooms. Reliable data is not available to measure the impact on our Juvenile Justice, Child Welfare, and Mental Health service systems.
- Local service systems need to maximize available funding streams through more creative approaches. This currently results in children being inappropriately placed in higher levels of care. (I.e. psychiatric care, PINS petitions, diagnostic units, detention).
- There is insufficient data and even less cross-system data available to track the number of units of service being provided, the number of children being served, or the number of homes and slots available at any point in time. With the expansion of community prevention programs such as the OMH waiver and B2H Waiver, the demand for planned and emergency respite will likely increase in the coming years. Some residential care agencies, TBH's, have apparent capacity to serve, but regulatory, supervision strategies and financing model(s) do not exist for cross-systems populations.

Research Activities

- Review of available literature (limited availability).
- Review of applicable laws and regulations of involved state agencies (OMH, OPWDD, DOH, OCFS, DPCA).
- Review of respite care services under HCBS Waivers in OPWDD, OMH, OCFS (B2H).
- Review of available hard data and information including sampling of local service delivery Plans across systems, select County social services information, indications of local utilization of respite services delivered in accordance with B2H service menus.
- Interviews from a sample of county and regional parent partners, Department of Social Services (DSS) officials, mental health (MH) officials, Youth Advocates, Single Point of Access (SPOA) coordinators, OPWDD officials and Developmental Disabilities Services Office (DDSO) representatives, Regional Technical Assistance Team (RTAT) leaders and members, OCFS youth, Coordinated Children's Services Initiative (CCSI) coordinators, planners, voluntary child welfare services providers, and others.
- Interviews with National Technical Assistance Center for Children's Mental Health at Georgetown University Center for Child and Human Development.
- Identification of local, state and national best practices.

- Presentation by Parsons Child and Adolescent Crisis Mobile Team.
- Interview with Ellis Hospital Emergency Room Administrator.
- Review of a sample of approximately 15 Local Service Plans across systems.
- Review of sample contacts with planned and emergency respite services providers.
- Participation in national webinar on respite care.

Systemic Recommendations and Strategic Directions (in Priority Order)

- If tasks related to strengthening respite care services are to remain a cross-systems priority, a clear and stronger commitment by the involved agencies will need to be made to develop consistent definitions, practice and financing models. As one example, each agency should be asked to conduct a thorough review of its respite services with a goal of identifying areas for shared training, collaboration, and resource utilization. Efforts to identify policy and practice differences among the state agencies must be rectified if a common respite practice is to emerge across children serving agencies.
- In the same vein, agencies will need to provide their expertise to develop the practice, business, and fiscal models for each of the respite services. Key program and fiscal staff will need to lend their expertise in this effort across systems to develop viable respite care alternatives.
- Ideally, respite care is one preventive strategy within a system of care that employs multiple prevention strategies to meet the needs of high-risk youth. CCF, through the implementation of the Children’s Plan and long-term commitment to cross-systems leadership efforts, is available to assist localities in developing local and regional systems of care and respite care services programs. Consultation with RTAT’s and appropriate state agencies will enhance efforts to improve local systems of care and building respite care capacity.
- As a component of model building, more accurate data is needed to identify the need for emergency and planned respite. This data needs to be broken down by county and by system. RTAT’s are an implementation partner resource. The Council on Children and Families is a resource identified in the Children’s Plan.

Short-Term Actions

- Respite Care is one strategic intervention in a cross-agency child serving system that requires increased coordination, collaboration, and access. The Council of Children and Families in implementing the Children’s Plan and building local systems of care can provide technical assistance in this effort with the assistance of state agencies.
- Treatment plans need to anticipate crisis situations and team members need to be well versed in addressing these needs. As a quality assurance measure, state agencies should review whether/how prevention and waiver programs are developing appropriate crisis diversion responses.
- Programs need to ensure the availability of culturally and linguistically competent respite programs that encourage familial informal and natural support networks to be available after services end.

- The original request to state agency and family representatives on the Workgroup for feedback on barriers in their respective agencies/systems by June 30, 2011 has been deferred until further notice.
- The provision of respite services must include children with a wide range of supervision needs. A demonstration allowing a downsizing of RTC's may provide valuable data on the cost effectiveness of respite, and assist in longer term financing preparation.
- A range of respite options from familial to group care options should be part of a flexible continuum of services. Some localities have paid an "on-call" per diem for approved Therapeutic Foster Care families that have provided some relief for emergency respite situations. This is the most cost-effective option next to a robust emergency response to crisis situations.
- Revisit and prepare regulatory amendment recommendations in order to better serve children with cross-system needs. (i.e., by enabling more flexibility with respect to mixing of ages and populations in planned and crisis respite programs and multiple state agency approval processes). As one example, if a respite provider is approved by one state system, that approval process should suffice for other state systems wishing to approve the same provider. Communities should develop protocols to anticipate the needs of children with complex needs (OPWDD & OMH eligible) and make a rapid response to these youth. (Ex. Oneida County agencies cooperatively planned for cross-system children's respite needs.)
- Adjoining counties need to work together to identify and respond to respite needs. The Workgroup recommends the continued strengthening of RTAT's, agency regional offices, and other regional groups be trained to help organize these responses.

Long-Term Actions

- Agencies should continue to conduct comprehensive, intra-agency reviews of their working definitions and implementation of respite care services with a report back to the Workgroup on efforts to standardize working definitions where feasible by June 30, 2011.
- The state's regulatory framework is not conducive to build a true cross-systems respite care services system without regulatory, financing, and practice models that are cross-systems orientated.
- Cross-systems crisis management training and mentoring opportunities must be developed, implemented, and administered for each child and family entering each agency's service system. The lack of agreed upon and consistent practice, business, and fiscal models is prohibitive in advancing respite care services conversations. Planned respite care and emergency/crisis respite care would each benefit from this tripartite paradigm.
- As a long-range strategy, a children's cross-systems reinvestment plan should be considered as one cornerstone for identified financial models. The possibility of a cross-systems sourced, dedicated funding stream for respite services and related supports has been discussed. In the immediate term, gathering useful data and information on ways select counties are ensuring that funding is flexible enough to follow the youth who needs temporary emergency respite placements.

- Additionally, another financial and funding cornerstone relates to ensuring the availability of and payment for respite care services through the present waiver services menus and derivatives as well as in any future waiver services enhancements, developments, and allowances by the Federal government.
- Any proposed financial-funding models should be tied to outcome metrics which in turn should be linked to performance outcome measures to promote a *pay for performance* financing framework based on quality.
- Explore and be prepared to address the development/replication of service-effective and cost-conscious mobile crisis teams for children and youth (e.g. Parsons Team) as an innovative service delivery direction and remain aware of the need for both urban/suburban and rural crisis team service approaches. Demonstration of the cost-benefit and value of such a proposition should be identified as a discrete task. An assessment/evaluation through the University at Albany, for example, may be proposed to further develop and advance this concept.

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