

## Focus Groups Executive Summary: Children with Emotional Disturbance and their Families – Needs Identification



The purpose of this Executive Summary is to report on four focus groups or “needs brainstorming sessions” held in May 2005 to solicit input from families, governmental agency stakeholders and other system partners involved with the children’s mental/behavioral health system in Nevada. The primary question posed to the groups: ***What do children with emotional disturbance and their families really want to help them live safe, healthy lives?***

### Background

The Nevada Division of Child and Family Services (DCFS) has established action strategies to facilitate the transformation of the children’s mental/behavioral health services system in Nevada to better meet children’s needs in their family homes and family-like settings in their communities. The overarching vision:

***Nevada’s children will have timely access to a full array of behavioral health treatment services that meet their needs in the least restrictive environment. Services will be delivered through a system of care model. Financing strategies will support quality service delivery and system stakeholders will act in concert to ensure that children’s needs are met.***

For information on current barriers to children’s safety and well being, along with short-term strategies designed to move the system toward the vision, please see:

<http://www.dcf.state.nv.us/Reports/TransformingChildrensMHWhitePaper040705.pdf>

DCFS recognizes that transformation will only be possible through shared accountability of improvement efforts. System partners and key stakeholders include families, youth, governmental agencies such as and the State Department of Human Resources’ Divisions of Health Care Financing and Policy (DHCFP/Medicaid), Health, Welfare, and Mental Health and Developmental Services (MHDS), as well as county child welfare and juvenile services agencies, treatment services providers, consortia, committees and commissions dedicated to guiding Nevada’s mental health services systems. Because Medicaid serves as the primary funding source for children’s mental/behavioral health services, particularly for children that are in state or county custody, changes will be made to the Medicaid State Plan and regulations to support the vision. Services, provider agreements, utilization review and continuous quality improvement activities must also be adjusted to realize the vision.

### Objective

The focus groups “needs brainstorming sessions” results will be used in finalizing revised Medicaid services definitions. Rates will then be linked to the services with treatment services provider agreements implemented reflecting the changes to definitions and rates.

## Methodology

**Four focus groups or “needs brainstorming sessions”** were held in May 2005. The three established Mental Health Consortia develop annual “needs assessments” for regions in Nevada, and therefore the focus groups were conducted in the form of brainstorming sessions to enhance and update existing needs assessments that each Consortium publishes as part of their statutory obligation. One DCFS staff member co-facilitated all four groups; a DHCFP staff member co-facilitated in Carson City and Reno, and the director of Parents Encouraging Parents (PEP) co-facilitated at the two sessions held in Las Vegas. Co-facilitators encouraged free-flowing discussion regarding children and families’ needs. Two of the four groups, Carson City and Reno, were tape-recorded and thus context and quoted commentary for identified needs is derived verbatim from those group sessions. The two Las Vegas groups chose to capture participants’ input by documenting a list of needs identified on flip charts. At the Carson City session, a vignette involving a family with a seriously emotionally disturbed child was used to generate targeted input on family needs. One DCFS administrative assistant attended all four sessions and ensured that notes were accurately kept.

**Seventy-nine participants** offered personal and/or professional stories regarding families’ needs. Participants were encouraged to share “wish list” type suggestions, things that they believe would enable children to be safe and healthy in family homes or family-like settings within Nevada communities. Participants were also asked to put aside perceived or real barriers that currently exist such as “no funding” and “wait lists” to meet identified needs in order to draw out creative suggestions on what families genuinely need rather than what is or is not available at present. The total of seventy-nine (79) participants in the four sessions does not include co-facilitators and the administrative assistant in the participant count. Government agencies were asked to minimize the number of agency participants in groups to best allow for families’ input in the process. Many of the family participants were also affiliated with PEP, serving as advocates for other families with emotionally disturbed children.

**May 10, 2005:** The Rural Mental Health Consortium hosted and the group was co-facilitated by a DCFS and a DHCFP staff member in Carson City. Participants included six family members, two treatment services providers, three DCFS Wraparound in Nevada contractors, one Health Division early intervention services staff member, and a participant from MHDS’ Rural Clinics. Participants were from Carson City, Silver Springs, Elko, and Lyons and Douglas Counties. The Elko participants joined the group by telephone. There were thirteen (13) total participants.

**May 18, 2005:** PEP hosted two groups at different sites in Las Vegas. Participants included twenty-one family members, seventeen treatment services providers, a court appointed advocate, one school district representative and one DCFS staff member. The groups were co-facilitated by the PEP director and a DCFS staff member. There were a combined total of forty-one (41) Las Vegas participants.

**May 19, 2005:** The Washoe County Mental Health Consortium hosted and group participants included four family members, twelve treatment services providers, five county child welfare staff, one county juvenile services staff member, two DCFS staff and a participant from the state Welfare Division. DCFS and DHCFP co-facilitated and there were a total of twenty-five (25) participants.

## Summary of Input

All four groups involved spirited discussion and valuable insight into what children with emotional disturbance and their families want to help them realize safe, healthy lives. While the input elicited from the four groups' sessions cannot be considered "hard data," it does provide qualitatively the feelings and opinions of participants, all of whom are involved with children needing mental health services in Nevada. The four groups' input has been summarized under broad categories:

- **Expanding Access & Types of Services**
- **Schools & Communities**
- **Training**
- **Funding**

Transcripts of the tape recorded sessions as well as flip chart content may be obtained by contacting Chrystal Main, DCFS Systems Advocate at 775-684-4453 or [cmain@dcfs.state.nv.us](mailto:cmain@dcfs.state.nv.us)

It is important to disclose that despite co-facilitators attempts to lead the groups toward needs identification rather than a discussion on system deficits or actual services, it was generally difficult to separate out "needs" from "services." For example, one group proposed a need for "crisis intervention teams." This could be considered a traditional (though unavailable) service rather than a need and the context of the group's discussion captures the distinction. As a family member in that group said, *"I'm talking about significant people in your family too as far as that team. I'm talking about grandparents, aunts, uncles, baseball coach, pastor or whoever it may be that can help stabilize the situation..."*

The perspectives shared from family members, treatment services providers, governmental agencies and other system partners illuminated frustration that, as one father stated, *"I have not seen any significant change in there and its been very frustrating to me..."* One mother's comment that *"they didn't understand what my kids needed as well as I did, because I had to live with them, and had to research it and you had to know or die..."* also recognized that families often understand the mental health needs of their children far better than professionals.

Despite participants' expressed frustration, they were very clear about what they wanted. Recurrent themes included a strong desire for in-home and school-based services, expanding Medicaid payment to "informal" supports such as parent advocates, peer support, family members on crisis intervention or "Family Response Teams," and increased opportunities for both children and their families to engage in recreational and/or activities that would help them keep their family unit intact. In addition, discussions centered on the need for specialized training and public awareness to reduce the stigma of mental health challenges. Finally, participants repeatedly discussed the need for more affordable and accessible services.

Likewise, participants articulated what they do not want. For instance, *"don't use 911 for mental health care,"* and *"the juvenile justice system shouldn't be our mental health care"* were repetitive comments. Participants emphasized that they wanted services to come to them rather than having to go to the services and did not want to have to change providers based on "the kind of Medicaid." Parents, in particular, stated that they did not want children expelled from school because that impacted their ability maintain employment. Last, one participant's statement regarding the provision of services to birth families captured the groups' discussions that they

did not want children to be placed with foster families in order to receive services, *“if I was allowed to provide the service I provide to foster parents to birth parents, which means the child is still in the homes and they have not been pulled, and they are not in the system...I’ve always felt, it could be very powerful, very preventative.”*

## Identified Needs

**Expanding Access & Types of Services:** Participants identified needs related to when, where they are able to access services, from whom they may access services, and the types of services children and families want to help them realize safer, healthier lives. Below is a brief summary of synthesized suggestions.

### When & Where

- 24 hour In-home Services (both telephone and in-person)
- “One Stop Shop” for the Whole Family (public and private providers co-located)
- School-Based Services
- “Safe Place” After School Programs
- Daycare Settings
- Juvenile Justice Agencies

### Who

- Eliminate Qualification/Licensing Barriers to Expand Service Providers
- Behavioral Aides in Schools
- Child Care Providers Trained in Behavior Management
- Respite Care Providers
- “Super Nanny” to Coach/Mentor Families
- Outreach Workers (reducing stigma and offering resource information)
- Tutors/Mentors
- Recreation and Social Skills Specialists
- Advocates (navigate the system, complete paperwork, locate resources, etc.)
- Support Group Facilitators
- Peer Mentors
- Child & Family Team Members
- Parents as Support/Advocates

### What - Types of Services

- In-Home Crisis Intervention Team
- Support Groups (social groups for youth, parents, family members)
- Family/Parent Mentoring
- Peer Mentoring and Peer Intervention (available to siblings too)
- After School Programs
- Individual Supervision After School
- Crisis Intervention Teams for Schools
- Parent-to-Parent Support
- Independent Living Skills Training
- Specialized Maintenance and Transition Planning
- Shadowing of Professionals
- Family Skills Building

- Specialized Support for Siblings
- Father-specific Support/Training
- Child & Family Teams (payment for attendance)
- “Debriefing Service” following crisis episode
- In-Home Assessments (to observe family/child interactions)
- Transportation (including reduced/free public transportation)
- Recreational Services to Support Growth such as summer camp, music lessons, sports
- Advocacy Services
- Subsidized Daycare
- Mental Health Courts
- In-Home and Out-of-Home Respite Services; Emergency Respite Services
- Recognition/Rewards for Kids

**School & Communities:** Participants in all four groups identified the need for increased awareness, training and support in schools and communities for families facing challenges related to their child(ren) with mental health needs. Some specific suggestions included:

#### Schools

- School personnel need mandatory training on mental health issues; train staff on how to deescalate behaviors.
- Schools need to be involved in Child & Family Teams, transition planning, and permitting children to remain in the same school regardless of out-of-home treatment placements that require the child to relocate temporarily.
- Services need to be provided in schools because that is where children spend a lot of time.
- Schools need crisis intervention teams to help keep kids in school.
- Peers need to be trained to help provide support in schools.
- Parents need more advocates to help them work with school personnel.
- Parents need to be recognized as experts on their children by school personnel.
- Behavioral Aides are needed to support keeping kids in school.

#### Communities

- Offer Outreach Workers to educate members of the community on mental health issues.
- Make “one stop” resource guide available (online) so that everyone in the community knows how to access service providers.
- Encourage neighborhood social activities and build a social network around families with children experiencing emotional disturbances.
- Offer more focus groups in the evenings.
- Develop cooperative agreements with public transportation for discounted or free rates for families.
- Free recreational activities for families including State Park passes and other public opportunities that currently cost money.

**Training:** The focus group participants identified specific groups that they believe need both awareness and specialized training to better assist families to lead safe and healthy lives. In particular, the following groups were identified as being most in need of training on mental health issues:

- Law Enforcement
- School Personnel
- Juvenile Justice Agencies
- Medical Professionals
- Child Care Staff
- Parents
- Siblings
- Peers in School

**Funding:** Although the topic of funding was discouraged to promote discussion regarding needs, participants in all the groups cited a need for flexible funding and “choice.” Specifically, participants said they wanted:

- Access to Medicaid benefits regardless of family earnings, even if it’s a sliding fee scale.
- Discontinuance of the practice requiring families to change Medicaid providers (HMOs v. other providers).
- Private insurance companies design coverage specifically for children.
- “Rethink Medicaid/Nevada Check-Up eligibility.”
- Assistance with SSI – should not have to be denied the first time.
- Access to Medicaid providers of dental and health care.

## Conclusion

The Division of Child and Family Services thanks the group participants for their commitment and dedication to changing how Nevada serves children with emotional disturbances and their families. A special thank you also goes to the facilitators of the four groups and the administrative assistant who ably supported this effort. Input from the focus groups “needs brainstorming sessions” has been provided to the workgroup revising Medicaid services definitions. This input will also be provided to the Children’s Mental Health Transformation Initiative Steering Committee on June 16, 2005.

