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Family Voice – System Recommendations

- **More Open Forums and Meetings**
 - **Variety of Formats**
- **Listen Better to Individuals and Families**
 - **Individuals and Families are the Experts**
- **Disability System Sustainability**
 - **Discuss National Best Practice with Family Focus Groups**
- **Family Voice is Critical to Providing Services**
 - **System Open to Listening to the Family Voice**



Family Voice – Services and Supports

- **More Flexibility of What is Funded and How it is Funded**
 - Solutions needed across the lifespan
 - One size doesn't fit all
- **Offer Services that Foster Self-Determination**
 - More choice and better options for quality supports
 - May 2015: 1255 (9.96%)
- **Create a Vision for the Future**
 - Families don't want to live a life in the system



Family Voice – Services and Supports

- **Specific Services and Supports**
 - Intense therapies
 - Early childhood services
 - Child care providers
 - Respite
 - Personal care attendants
 - Aging supports
 - Independent supported living arrangements
 - ***Relationship building and valued roles***



Joining Circles: Relationship Building and Valued Roles



- **Activities Alone are Unlikely to Lead Towards Meaningful Relationships and Community Connections.**
- **Moving from Activity to Connection**
 - **Activity = pleasant events, positive interaction, skill development**
 - **Connection = strategically focused on deepening connections.**



Joining Circles: Relationship Building and Valued Roles

- **Benefits of Natural Supports**
 - Supports self-determination
 - Supports independent living
 - Shifts away from specialization – breaking stereotypes, teaches and educates
 - Provides normalization
 - Never enough money for paid support
 - Breaks segregation/parallel systems





Joining Circles: Relationship Building and Valued Roles

- **Job Description – Human Service Staff**
 - Build community connections and assist persons with disabilities in having more friends
 - Work towards a goal to widen the person's circles of relationships with people without disabilities based on strengths, interests, preferences
 - Know the community and the people within it
 - Act as the bridge between people with disabilities and the larger community



Joining Circles: Relationship Building and Valued Roles

- **Obstacles for Support Coordinators**
 - I don't have time to do this work!
 - I have over 100 individuals on my caseload!
 - I can't spend my time in front of the computer eight hours a day!
 - You were two individuals that had nine months to make connections for 12 individuals.



Joining Circles: Relationship Building and Valued Roles

- **Suggestions for Agency Practices**
 - Focus on capacities and gifts rather than correcting deficits
 - Be willing to experiment and maybe take some risks on community relationships and friendships
 - Start large conversations with all the “powers that be” for the importance of relationships
 - Prioritize the staff role of supporting friends and full community belonging, staff evaluations
 - Redefine staff roles, incorporating the ideas of: community connector, social guide, chaperone
 - Trust the natural capacity of the community, and provide sufficient support for that capacity
 - Recognize that small changes can make a difference and overall change will take a long time



Joining Circles: Relationship Building and Valued Roles

- **Areas to Watch**
 - Thinking that all this will cost more money or require more staff
 - Requiring community people to be volunteers, rather than “just friends”
 - Turning friends into volunteers (special awards, formal training programs)
 - Using “liability” as a justification for not supporting individuals in having as integrated and independent life as possible.
 - Using “risk-taking” or “trusting the community” as a justification for carelessness or thoughtlessness
 - Trying to “over-program” and “formalize” friendship



Family Voice – Support Coordination

- **Conflict-free Support Coordination**
- **Decrease High Turnover**
- **Oversight for Quality Assurance**
- **Ensure Qualified Professionals and Organizations**
- **Increase Pay for Direct Support Professionals**
- **Manageable Workloads**
 - **Increases ability to focus on individuals**
 - **Increase quality and allow time for relationships**
- **Support Interdisciplinary Team Approach**
- **Ensure Choice**



- **The New Home and Community Based Waiver Rule (HCBS) and Why it Should Matter to Self-Advocates and Families**
- **6 standards that all HCB services need to meet:**
 - **Integration into the Community.**
 - **Individual Choice.**
 - **Individual Rights.**
 - **Autonomy.**
 - **Choice Regarding Services and Providers.**
 - **Person-Centered Planning.**



- **Robin Cooper**
 - National Association of States Directors of Developmental Disabilities Services (NASDDDS)
 - May 4, 2015; St. Louis
 - May 5, 2015: Columbia
 - May 6, 2015; Kansas City
- **Video Available**
 - http://moddcouncil.org/?page_id=whatsnewstory&id=27



Thank you!

