Institute #24

Serving Youth with Intellectual/Developmental Disabilities and Substance Abuse Challenges in Systems of Care

Agenda

Focus of this session is on system change and Medicaid service delivery from the state level

Emphasis on developmental disabilities services

Some common threads

Family perspective

Lessons Learned and Tools from Arizona

Lessons Learned and Tools from NJ

Introductions

Robert Klaehn, Medical Director
Division of Developmental Disabilities, AZ

Maureen Mills, Family Support Specialist,
Raising Special Kids, AZ

Ruby Goyal-Carkeek, Deputy Director,
New Jersey Department of Children & Families

Kathy Enerlich, Executive Director
PerformCare, NJ

Diane Jacobstein, Senior Policy Associate &
Clinical Psychologist, Georgetown

Two exemplary but very different state-wide models

• Strong commitment to listening to families

• Smart use of data to drive system improvement and proactively identify service gaps

• Thoughtful use of contracts to assure accountability and best practices

• Training provided and mandated for providers to assure best practices

Both systems created in response to families' advocacy for system reform

Importance of Inclusion

• Stakes are high

• High risk of incarceration, out of home placement, referrals to child welfare, homelessness

• Over-reliance on tertiary care is very ineffective and inefficient
First Principle: Listen to Families
• Stress may be unrelenting
• Long painful search for help
• Exclusion from many programs
• Families often say they feel blamed and disrespected
• Burden of fragmented service systems
• Dearth of services in many communities
• Often layered on other social justice issues

Specialized Expertise is Critical
• Examples with Developmental Disabilities
  – Psychiatric symptoms may present very differently with ID than in general population
  – Often missed: Diagnostic overshadowing
  – Trauma much more prevalent- often unrecognized
  – Untreated medical conditions and adverse drug reactions drive many crises

Goal to Infuse Expertise
• to increase the knowledge base and comfort level of providers in the community, rather than rely on a small group of providers with appropriate skills
• ongoing consultation with multidisciplinary team of experts

Appropriate Service Array
Examples:
• Comprehensive evaluations are critical
• Specialized treatment approaches
• Adapted trauma treatment
• Therapeutic, planned respite

Resource: Effective Strategies Checklist

- Functional communication
- Alternative, Augmented Communication
- OT
- Autism-specific treatment

Resource: Effective Strategies Checklist: Children and Youth with Developmental Disorders and Challenging Behavior

- Effective Strategies Checklist: Children and Youth with Developmental Disorders and Challenging Behavior
- Discrimination and conflict
- High rates of self-harm
- Psychiatric symptoms may present differently
- Diagnostic overshadowing
- Trauma much more prevalent
- Untreated medical conditions and adverse drug reactions drive crises

Review Critical Information for Administrators and Clinicians
- This is an extremely heterogeneous group of individuals with differing strengths and needs.
- There are no one-size-fits-all approaches.
- The presence of psychiatric disorders is much higher than generally recognized among adults and youth with intellectual disability (ID; reference is to estimate 10%)
- ID refers to any other "learned" processes that affect as well as "mental retardation a disability in learning to perform certain life activities, including academic skills..."