PONDA Network
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PONDA Special Needs Strategy Recommendations: How Should the System Look?

1. Functional impairment and child-environment interactions should be the drivers of service delivery not "medical diagnoses" (or psychology diagnoses).

- A medical diagnosis (e.g. "autism spectrum disorder", "alcohol related neurodevelopmental disorder", etc.) tells relatively little about the services required by an individual child and family and relying on diagnosis alone may lead to inappropriate or inadequate service.
- Children with the same impairments require individualized supports and services depending on their unique environments (e.g. family stressors, school factors)
- Many children who do not have "medical" diagnoses have severe functional impairments and need services.
- Comprehensive assessment of functional impairments and children's environments informs to a large degree what supports are required
- The "environment" (e.g. classroom, home, daycare) is often the most effective target of intervention rather than the child

2. A common language for description of child and family strengths and vulnerabilities should be used by all agencies including developmental, educational, mental health, and social services

- A common biopsychosocial formulation should replace the traditional medical diagnosis as the primary means of understanding a child's situation
- A common language would allow all care providers to develop a shared picture of a child and family's strengths and vulnerabilities leading to a coordinated plan of care
- A common system could be used, understood and contributed to by service providers across developmental, mental health, health, and educational agencies
- All areas of functioning would be described using "can do" language

- The common system would include all major areas of functioning and environment, including:
    - Child's Interests, Strengths
    - Learning and applying knowledge (e.g. reading, reading comprehension, maths)
    - General tasks and demands
    - Communication (e.g. Verbal/Language Ability, nonverbal/visual ability)
    - Mobility (e.g. motor ability)
    - Self-Care
    - Domestic Life
    - Interpersonal interactions and relationships (e.g. emotional/interpersonal, social abilities)
    - Major life areas (e.g. family strengths and vulnerabilities, daycare, school)
    - Community, social and civic life (e.g. leisure activities, sports)

3. A child and family centered system uses just enough assessment in order to make decisions

- Repeated assessments when a child and family's needs cross agencies should be minimized
- Agencies should use common assessment tools to reduce the need for repeated assessments
- Assessments should be customized and address presenting needs i.e. not every situation requires in-depth assessment
- Resources not spent on assessments can be re-deployed for service
- "Intake" should be streamlined and shared between agencies, to avoid duplication

4. Early Intervention

- Scientific literature is clear that a child's brain is most affected by early experiences (those between 0 and 3 years old). Early interventions should be prioritized to reduce the risk of long term disabilities. These should include:
    - Poverty reduction from conception to 3 years
    - Treatment of mental health disorders in parents of young children
    - Early treatment of parent-child interaction difficulties
    - Affordable (or public) high quality daycare
    - Further expansion of enriching early learning opportunities, such as programs at recreation centers and libraries for parent and child

5. Long term support when needed

- Despite intense intervention, a small number of situations are not amenable to change and long term support is required either continuously or intermittently
- Emphasis should be on care coordination and integration into environments (participation in school, recreation) rather than "fixing" the child
- A “serve, discharge, and get back on a waiting list for more service” approach does not provide appropriate support for families with ongoing needs
- Examples of situations that may require ongoing supports include:
    - Families of children with severe neurodevelopmental disabilities such as severe communicative, cognitive, motor or complex medical conditions
    - Families facing significant psychosocial adversity

6. Direct referrals between agencies

- Children and families who have been comprehensively assessed should be referred directly to the appropriate service provider without requiring reassessment in the receiving agency (e.g. physician or psychologist referring a child diagnosed with an anxiety disorder directly for mental health therapy)
- Providers should have access to information regarding services in all community agencies
    - Up-to-date eligibility and exclusion criteria and wait times should be made available by each agency on an integrated website accessible to service providers and parents (particularly important for larger communities with multiple agencies funded by different ministries)
- Single point of access services can be a barrier for those who have already had a comprehensive assessment of their needs and can lead to delays in starting treatment

7. Coordinated transition to school

- Therapists (e.g. Speech Language, Occupational Therapy, Physiotherapy) working with preschool children in Children’s Treatment Centres should collaborate directly with their counterparts in schools (i.e. clinician to clinician handover)

8. Electronic records

- An electronic repository of relevant information (e.g. assessments, services provided) is required to facilitate communication and enhance care coordination
- Records need be accessible to service providers across agencies including developmental, mental health, and educational agencies

- A “personal developmental file” for each child in ownership of the caregivers could facilitate the communication between service providers and different agencies

9. Care Coordination

- Care coordination should be determined on a case by case basis and based on an assessment of needs:
    - minimal care coordination may involve periodic telephone conversations and management of the child’s clinical data
    - advanced care coordination may involve meeting with other care providers involved with the family, more frequent counseling
    - intensive care coordination may involve regular meetings, in home service, and advocacy at community tables with an emphasis on longitudinal involvement with the child and family
    - care coordinators should be capable of long term involvement with children and families and should be appropriately funded
- Families should have influence on who is taking on their care coordination

10. Children’s Mental Health services should be available to all children

- Children with developmental disorders should have the same access to mental services as other children and youth
- Mental health and developmental service providers need to collaborate directly in the care of children and families
- Service providers for mental health needs in children with developmental disabilities need to have training in both areas or collaborate with experts from the area they lack training in order to provide evidence based interventions