

This is a preliminary summary of themes based on focus groups and interviews conducted with Iowa caregivers of children and youth with special health care needs in July and August of 2019.

FAMILY PROFESSIONAL PARTNERSHIPS

- Provider did not listen to concerns or take them seriously
- Mistreatment due to having Medicaid
- No one is asking about caregiver health and affirming what they are doing
- Overwhelmed with paperwork post-diagnosis – no direction on what to do/where to send
- Educate physicians to listen to parent concerns and take them seriously

MEDICAL HOME

- Have to engage with multiple physicians to discover options for child's needs
- No one with expertise in rare conditions
- Long wait times
 - ER, dental treatment (1 procedure at a time), appointments with specialists (3 months or more after referral), respite (2 years)
- Information on transitions & developmental stages
- Easier scheduling
- Referral delays
 - Have to fight and advocate and go through multiple appointments before referral is given for specialists or diagnostics
- Hospital discharged too soon (repeated and more serious hospitalizations)
- Need training for health and dental providers and health care staff on children with special needs

INSURANCE AND FINANCING

- MCO/Medicaid problems
 - Limited # of providers and service options
 - Communication with and getting approval
- Communication with providers regarding approval of care
- Lack of coverage for meds/supplies/services for special needs
- High deductibles
- Gap in coverage for adopted newborn
- Not qualifying for Medicaid
- Costs of services
- Accumulation of debt related to care/supplies
- Federal funding cut for play therapy

CULTURAL COMPETENCE

- Racism at primary care provider office
- Fear of going to the hospital due to racism
- Need cultural competency training for providers

EASY TO USE SERVICES AND SUPPORTS

- Transportation service took a long time and was with other people – triggered child with autism
- Unaware of resources available
- Unavailability of services/supplies
 - Local supplies for CHYSHCN, child mental health services, childcare
- Provider gaps: Developmental doctor, occupational therapy, physical therapy, respite, nursing services
- Support/assistance navigating the system
- Increased availability/accessibility/knowledge of resources
- Improved service coordination (education system, nursing services)
- Need more services and supports available after age 5
- Need accommodations/accessibility for CYSHCN
 - Diaper changing facilities, adapted shopping carts, adapted playground equipment, adapted equipment/facilities in other community places
- Need local advocates/liaisons
- Need training for school staff and day care providers
- Need family/peer support groups
- Need adaptive technology specialists
- Need local special Olympics

TRANSITION TO ADULthood

- Need information about adult services, waivers/financing, legal issues

EARLY AND CONTINUOUS SCREENING AND REFERRAL

- Change in ability of foster parents to schedule appointments – nearly impossible to get needed care for foster children with special health care needs
- Easier/quicker referrals
- Earlier/accurate diagnoses
- Referral gap (if referral to AEA isn't before 3, have to wait until school starts to receive services)
- Passed around a lot