

This is a preliminary summary of themes based on focus groups and interviews conducted with Iowa caregivers of children 1 to 11 years old in July and August of 2019.

PROVIDER ISSUES

- Not listening to patients
- Dismissing patient concerns
 - Delays in care, inappropriate treatment, and permanent health consequences
- Communication problems including vocabulary used
- Misinformation from doctors
- Discrimination
- Lack of consistent providers and care
- Not taking new patients
- Do not accept Medicaid
- Long waitlist for waivers
- Lots of planning and time necessary to get care
- Poor coordination between primary care and specialists

SERVICES NEEDED OR DESIRED

- Respite and childcare
- Non-Emergency Medical Transportation
 - Evenings and weekends for urgent care
- School bus monitoring
- More activities and programs
 - Integrated physical/social activities, winter activities, sex education inclusive of trans/non-binary children, suicide prevention
- More information and resources
 - Holistic health and wellness, parenting, child development, mental health
- System navigation support
- Specialized services
 - Play, speech, physical, mental health, occupational and equine therapies, hearing services, postpartum and breastfeeding support, migrant services, ancillary services
- Safe spaces for activities
- More parks
- Supports to maintain insurance coverage across changes/transitions
- Streamlining insurance process
- Support for keeping appointments
- Supports to address stigma associated with medical conditions/diagnoses

ACCESS ISSUES

- Cannot find specialized services needed such as mental health or autism services
- No long-term care options
- Cannot get time off work for multiple appointments
- Poor coordination between doctor, insurance, medical companies, and pharmacy
- Lack of transportation
- Caregiver disabilities
- Stigma associated with identity/medical diagnosis
- Authorization requirements to get medically necessary prescriptions
- Unable to purchase medical supplies due to citizenship status
- Untreated mental health disorders
- Winter rural road conditions
- Lack of local pediatric specialists
- Lack of dental care providers
- Don't know services that are available
- Parents unavailable when care is available
- Language barriers
 - Communication through phone interpreter is difficult
 - Medicaid information is unavailable in primary language
- School-based health services (ST, PT, OT) unavailable during summer
- Not enough delay to qualify for primary care provider recommended school-based services
- System fatigue
- Parent personal issues
 - Mental health, substance abuse, GERD, respiratory illness, SPD, ADHD, cerebral palsy, domestic violence, obesity, isolation, hopelessness

INSURANCE ISSUES

- Limited options
- MCOs/Medicaid
 - Gaps in coverage during transitions
 - Denials