Raising a Child with a Disability

Diane Kearns, Parent

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About the Mama Bear

• Professional, working mother
• College graduate
• Daughter of 1ˢᵗ generation Americans (Philippines and Ireland), married to the son of 1ˢᵗ generation Americans (Russia and Austria)
• Although not born in Texas, “I got here as fast as I could”
• A “fixer” of injustices
• Loud, squeaky wheel, mama bear
• “No” means “Keep going until you get the answer you need”
About the Cub

- Twins born at 32 ½ weeks (now 13-years-old); 6 weeks in the NICU
- Daughter has no disabilities; son had early diagnosis of cerebral palsy, and later visual impairment diagnosis at 12 months
- First wheelchair at age 3
- Seizure disorder appeared at age 8
- Multiple surgeries: Strabismus, Tonsillectomy, Botox, Baclofen pump
- Attends public school: Life Skills class & inclusion in typical classroom
- Plays baseball with the Miracle League, Team Bravo Gymnastics at the JCC, Kayaking at Texas Rowing for All. Last year zip-lined for the first time at Texas Lions Camp.
Raising a special needs kid is REALLY hard

• There’s no manual, and what if there’s no diagnosis?
  • Health insurance won’t pay for specialists or therapies without a diagnosis

• Huge medical costs
  • Even with private health insurance, not everything is covered
  • Navigating a High Deductible Health Plan (deductible, co-insurance payment, out-of-pocket maximum, explanation of benefits)
  • It’s close to impossible for Middle Class families to qualify for Medicaid services for their disabled child

• Exhausting: both physically and mentally
  • Rate of divorce from 70% to 80% compared to 50% national average – single moms raising kids with special needs is prevalent
  • Need for Respite
  • Worrying “am I doing enough?”
  • Frustrating: lots and lots of crying
The influence of Race, Education & Income

• The below issues are common across the population, but are amplified with minority families, those that have a low education or low income:

• Fear and lack of education
  • I’m afraid no one will take care of my child like I can; missed opportunity to learn from educators/therapists/aides
  • I’m afraid my child will be the object of ridicule; Inclusion works for special needs & typically developing kids
  • I’m afraid people will think I’m stupid; never be afraid to ask

• Communication barrier prevents parents from getting services they need for their children
  • There is no one to translate what the doctor/nurse is telling me so I can’t effectively take care of my child
  • It’s complicated navigating the system; why do I have to wait on a list? What does it get my child?

• Giving up on the system
  • There’s nothing else I can do
  • I don’t want a handout
Texas Medicaid Waiver Programs

• Intent is to keep people with disabilities in the community and not in an institution, but there are far too many people on the interest lists and not enough getting services

• Texas programs for children
  • Based on the individual’s income NOT family income
  • Programs include: Medicaid, Respite, Attendant services, Home Modification, Vehicle Modification

• But you have to wait for it: Interest Lists
  • Over 100,000 Texans on a Medicaid Waiver Interest List
  • As of March 2016, the number of people on the interest lists:
    • Medically Dependent Children Program (MDCP): 18,221
    • Community Living Assistance & Support Services (CLASS): 55,874
    • Home Community-based Services (HCS): 77,379
  • People enrolled in the program in the last biennium:
    • MDCP: 448
    • CLASS: 155
    • HCS: 1,308

• It still isn’t the be all & end all:
  • That DME isn’t covered because it is not on the list: ramps vs. lifts, laptops vs. iPads
What can we do?

• Remove the barrier for care
  • Cover basic medical needs
    • Need primary care physicians, not just emergency room visits
  • Provide access to services
    • Middle class families can’t get Medicaid services; Medicaid buy-in program
  • More access to prenatal care for high-risk populations (i.e. teen mothers)
    • Genetic testing, ultrasounds, vitamins

• Better communication
  • Support multilingual translation by using technology – make it easy to access the Internet through mobile devices and use translation software
  • Centralize information & make it accessible via the Internet
  • Share info on scientific breakthroughs – minimize debilitating effect of the disability
  • Leverage parents and parent resource groups (like Texas Parent to Parent – txp2p.org)
Wait, there’s more!

• Coordinated care
  • It can’t just be the parents coordinating care with specialists, therapists, etc.

• Need more healthcare professionals
  • Not enough psychiatrists: kids with ADHD and Mental Health concerns have to wait more than 3 months for an initial visit; Psychiatrists will only provide 30-day refills
  • See specialists in another state
  • Need more doctors assessing special needs kids for Medicaid qualification: An OBGYN assessed my son’s MDCP denial case

• Update policies
  • Why are some DME items covered & others not?
  • Wheelchair covered, but not the seat; Brakes not covered; Seatbelt not covered
  • Keep up with technology!
  • Wheelchair “lift” (covered) vs. wheelchair “ramp” (not covered)
  • Communication devices: personal computer (covered) vs. iPad (not covered)
  • In Texas we are launching the Star Kids program
Summary

• The 2015 United Cerebral Palsy The Case for Inclusion report ranks the state of Texas #50 out of 51 in quality of life for people with disabilities – we need to fix that

• Increase access to healthcare for children with disabilities – address policy issues, funding, interest lists, communication – whatever it takes to reach more kids and their families

• Transition to adulthood: Provide jobs for people with disabilities
Thank you!