

## Work Group Challenges

### I. Specialty Group

- **Providers**

1. Lack of information about services available for pediatric and adult services.
2. Completing annual exams to assist with identifying specialty needs vs emergency room use.
3. Data base to track outcome of transition youth.
4. Falling through the cracks, not following through with health care.
5. Access to specialist in the same county within managed care organization.
6. Identifying appropriate adult –orientated providers for youth/adult during transition.
7. Identifying adult providers and supporting their training to care for children with special health care needs.
8. Recruiting: identifying in state licensed specialized care providers.
9. Engaging adult providers and youth into this workgroup.
10. Engagement of providers (clinicians) on transition: learning, quality improvement, seeing patients, and coming to these meetings.
11. Lack of knowledge about transition among providers, youth, and families.
12. Lack of knowledge about whom to hand youth off
13. Education of adult providers about special needs youth transitioning.

- **Insurance**

14. Insurance availability limits option. Many providers accept only a few insurances.
15. Limited resources/providers are available in rural communities, especially across county lines.

- **Parents and Patients**

16. Transportation to/from medical providers is limited in rural communities, especially across county lines.
17. Often the best way to engage the medical providers in rural communities is teleconference because travel to/from presentations is difficult.
18. Education in the importance of self-directed care for ages 13-18.
19. Enhance training to special populations, ie. Foster care focused.
20. Education of parents, caregivers, about referral and transition process.
21. Common set of referral processes for youth and providers for pediatric to adult care.

- **State agencies and Community Based Organizations**

22. Lack of agreement statewide among providers as to information and preparedness ordered, and to make the transfer successful.
23. Lack of coordination between pediatric and adult agencies. Ex. AAP, ACP, AAFP.
24. Variability among specialist regarding transfer to adult specialist.
25. Uniformity in pediatric approach for readiness expectation, skills for youth moving to adult health care.
26. Often the best way to engage the medical providers in rural communities is teleconference because travel to/from presentations is difficult.

## **II.Primary Group**

- **Provider**

27. Inventing adult and pediatric doctors to spend the time needed for smooth transition-ie pay for it (need accurate codes)
28. No financial incentives for transition
29. Little guidance around addressing guardianship and capacity building (especially for youth with intellectual disabilities) MDLC
30. Connecting former foster care youth to health insurance
31. Ensure theta transitional youth are connected to a provider(CPC)
32. Helping youth to select a health care proxy
33. Transition planning starts too late
34. Lack of time during well visit to address transition.
35. Staffing and personnel at local, community levels. Ex. LHD, Primary Care Physicians.
36. EHR problems
37. Data- state and local levels
38. Registries
39. Appropriate training for adult clinicians so that they are prepared to care for young adults with special health care needs.
40. Lack of education for providers about how to bring up, address, and trade transition.
41. Lack of provider (physicians) awareness of importance of transition.
42. Identifying adult PCP's.
43. Access
44. Link pediatric and adult PCP's within communities.
45. Adult providers not yet part of the solution.
46. Skill building
47. No HER tools to facilitate documentation, billing for transition services.
48. Six core elements transition model is new – we are at the start.
49. Lack of standard guidelines
50. A place to land – clinicians who are comfortable caring for young adults with special health care needs.

- **Insurance**

51. Insurance changes – care coordination time commitment for pediatricians handling off and internet receiving these patients is enormous. We need remunerations for this issue.
52. Funding and reimbursement

- **Parents and Patients**

53. Family awareness of health care transition
54. Supporting cultural shift to value transition.

### III.Supporters

- **Insurances**

55. Types of insurances, coverage types
56. PACT- Parents and children Together: funding, screening, health care coverage, teams working together, agencies, access to care, transportation.
57. Camps- enough time to serve needs, building communities, providing parents with respite, funding.
58. Funding school year when LD – vs recreation activities and teaching self-management.

- **State agencies and Community Based Organizations**

59. School nurses left out of IEP and working with transition planning.

- **Providers**

60. Identify willing providers, and knowledgeable, receptive, willing to be trained.
61. Lack of providers in rural areas.
62. Lack of education of parents and primary providers.
63. Difficulty in parents and students understanding the process.
64. Resistance by primary providers with assisting youth with serve disabilities.
65. Doctors and staff understand the various challenges and impacts of ASD.
66. No legislation regarding transition that is universal within each county.

- **Parents and Patients**

67. Parents not really ready to deal with transition
68. Parents just thinking about today, not 5 years down the line.
69. Developmental age vs actual age and phases of life.
70. Parents not knowing what's available in county.
71. Staff not knowledgeable about what to recommend to parent for resources.
72. Missed appointments – some providers will release a patient after 2 missed appointments or refuse to see them.
73. Compliance- following treatment, taking medicines.
74. HIPAA vs effective Health Care: (1) Involve patient in care (2) Poor Hygiene- leading to chronic conditions, like vaginitis, UTI, dental issues (3) confabulations- inability to accurately report medical history (4) Symptoms.
75. Receptive language- looking like they understand. Get treated for wrong stuff.
76. Executive and Adaptive functions: reminders to take meds, follow treatment when at home, don't plan ahead to take meds when they go out. Don't take meds even if parent packed them (alarms, etc. work).