

Definition of “Complex” for Shared Care Planning

Children and youth with special health care needs (CYSHCN) are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998).

For the purposes of shared care planning, CYSHCN are considered “complex” if they have:

- (a) a medically complex condition *or*
- (b) *both* a health condition *and* social complexity.

CYSHCN with **MEDICAL COMPLEXITY** “have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for or use of medical technology” (Kuo & Houtrow, 2016, p. e1).

- Examples
 - i. A child with a genetic syndrome with an associated congenital heart defect, difficulty with swallowing, cerebral palsy, and a urologic condition. The child requires the care of a primary care physician, pediatric subspecialists, home nurses, rehabilitative and habilitative therapists, community-based services, pharmaceutical therapies, special nutritional attention, and durable medical equipment.
 - ii. A child with a chronic neurodevelopmental disability in need of assistance with medical equipment, such as a tracheostomy and gastrostomy tubes.
- Functional limitations are restrictions in the child’s ability to do the things typically developing children of the same age can do in their daily lives. The limitations may be permanent or temporary. Examples include inability to perform tasks like dressing or walking or unable to participate in life events like attending school. More information is available on functional limitations in the World Health Organization’s *International Classification of Functioning, Disability, and Health (ICF)*.

CYSHCN with **SOCIAL COMPLEXITY** have a physical, developmental, behavioral, or emotional condition and they or their families have experienced one or more of the following:

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| 1. Adolescent exposure to intimate partner violence | 10. Low English proficiency |
| 2. Child abuse/neglect – child welfare system involvement | 11. Low parent educational attainment |
| 3. Child criminal justice involvement | 12. Parent criminal justice involvement |
| 4. Child mental illness | 13. Parent death |
| 5. Child substance abuse | 14. Parent domestic violence |
| 6. Discontinuous insurance coverage | 15. Parent mental illness |
| 7. Foreign born parent | 16. Parent physical disability |
| 8. Foster care | 17. Parent substance abuse |
| 9. Homelessness | 18. Severe poverty (TANF eligible) |

Source: Center of Excellence on Quality of Care Measures for Children with Complex Needs, University of Washington & Seattle Children’s Research Institute, 2016