APPENDIX B- USING ICD-9 CODES TO IDENTIFY CYSHCN

Please see the attached Excel Spreadsheet for the List of Specific ICD-9 codes that can be used to identify CYSHCN. These codes are based on the following sources:

1. **Deaths Attributed to Pediatric Complex Chronic Conditions by Feudner, et al**. This list represents a modified list of codes used in a retrospective longitudinal study of mortality patterns in Washington State - which was based on studies of hospitalization patterns of children with costly illnesses and congenital defects. The authors modified the list to include epilepsy and by expanding the range of ICD-9 codes for the subcategories of: mental retardation; central nervous system degeneration and disease; and malignancy.
2. **Center for Infants and Children with Special Needs Care Coordination Toolkit.** These codes were contributed by the providers who participated in Carl Cooley's 2001 Learning Collaborative, Building a Medical Home: Improvement Strategies in Primary Care for Children.
3. **Cincinnati Children's *Children with Special Health Care Needs Identification Project*** (155 pediatricians/38 practices) which identified that 30% of patients have at least one chronic condition when they completed data claims runs (hospital and practice-based). Hypothesizing that this was an over-estimation of children needing focused care management; the providers reviewed the patient list and refined it based on 15 factors (i.e. multiple chronic conditions or one chronic condition that was not well-controlled). This resulted in an average of 15% of the patient panel being identified as needing care management. From there the providers divided list into two categories – always included and conditional, meaning only conditional patients needed chart reviews.
4. **Adoption and Foster Care Analysis and Coding System: AFCARS Disability/Special Needs Table.** This table lists several medical/emotional conditions that may be mapped to AFCARS data elements for foster care and adoption. It is not an exhaustive list of all conditions that states may used for reporting; it is also important to note that AFSCARS does not utilize ICD-9 codes, but rather utilizes diagnosis groups.
5. **New Codes as noted in Coding for Pediatrics 16th Edition of American Academy of Pediatrics.** The International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) for 2011 identified more than 150 new codes, revisions and deletions effective October, 2011.