Supplementary Materials

**Supplemental Table 1: Characteristics of children ages 0-5 with CHD associated with any neurodevelopmental services**

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| --- | --- | --- |
|  |  | **Receipt of specific neurodevelopmental services****by unique individuals, n (%)** |
| **Characteristic** | **Any Encounter***1***n (%)** | **No Encounter** **n (%)**  | **p-value***2* | **Developmental Testing** | **Psychological Testing** | **Neuropsychological Testing** | **Mental Health Assessment** | **Mental Health Intervention** | **Health and Behavior Assessment** | **Health and Behavior Intervention** |
| Total population (n=296) | 49(17%) | 247(83%) |  | 20(7%) | 19(6%) | 2(1%) | 21(7%) | 12(4%) | 4(1%) | 0 |
| Sex |  |  |  |  |  |  |  |  |  |  |
|     F | 19 (15%) | 109 (85%) |  | 6(5%) | 5(4%) | 0 | 10(8%) | 6(5%) | 1(1%) | 0 |
|     M | 30(18%) | 138 (82%) |  | 14(8%) | 14(8%) | 2(1%) | 11(7%) | 6(4%) | 3(2%) | 0(0%) |
| Childhood Opportunity Index quintile4 |   |   | 0.3 |   |   |   |   |   |   |   |
|     Very Low | 12(17%) | 57(83%) |  | 6(9%) | 3(4%) | 0 | 4(6%) | 1(1%) | 2(3%) | 0 |
|     Low | 6(11%) | 47(89%) |  | 1(2%) | 1(2%) | 0 | 5(9%) | 0 | 0 | 0 |
|     Moderate | 15(25%) | 45(75%) |  | 6(10%) | 8(13%) | 1(2%) | 5(8%) | 6(10%) | 1(2%) | 0 |
|     High | 9(15%) | 50(85%) |  | 4(7%) | 4(7%) | 0 | 5(8%) | 3(5%) | 0 | 0 |
|     Very High | 7(13%) | 48(87%) |  | 3(5%) | 3(5%) | 1(2%) | 2(4%) | 2(4%) | 1(2%) | 0 |
| Rurality |  |  | 0.11 |  |  |  |  |  |  |  |
|     Rural | 25(14%) | 156(86%) |  | 10(6%) | 12(7%) | 2(1%) | 11(6%) | 6(3%) | 1(1%) | 0 |
|     Urban | 24(21%) | 91(79%) |  | 12(10%) | 7(6%) | 0 | 12(10%) | 6(5%) | 3(3%) | 0 |
| Insurance |  |  | 0.7 |  |  |  |  |  |  |  |
|     Commercial5 | 19 (16%) | 102 (84%) |  | 4 3%) | 4(3%) | 2(2%) | 11(9%) | 7(6%) | 3(2%) | 0 |
|     Medicaid | 30 (17%) | 145 (83%) |  | 16(9%) | 15(9%) | 0 | 10(6%) | 5(3%) | 1(1%) |  0 |
| CHD Diagnosis |  |  | 0.2 |  |  |  |  |  |  |  |
| Single ventricle with arch obstruction | 12(11%) | 99(89%) |  | 8(7%) | 2(2% | 1(1%) | 5(5%) | 3(3%) | 1(1%) | 0 |
| Single ventricle without arch obstruction | 31(20%) | 127(80%) |  | 11(7%) | 15(9%) | 0 | 14(9%) | 8(5%) | 2(1%) | 0 |
| Two ventricle with arch obstruction | 3(21%) | 11(79%) |  | 0 | 1(7%) | 1(7%) | 1(7%) | 1(7%) | 0 | 0 |
| Two ventricle without arch obstruction | 3(23%) | 10(77%) |  | 1(8%) | 1(8%) | 0 | 1(8%) | 0 | 1(8%) | 0 |
| Distance from care centers |  |  |  |  |  |  |  |  |  |  |
| Less than 100 km from nearest regional pediatric center (Bangor, Portland, Boston) | 46 (17%) | 228 (83%) | 0.5 | 19 | 19 | 12 | 4 | 0 | 2 | 17 |
| Less than 100 km from nearest surgical center (Portland, Boston) | 35 (18%) | 164 (82%) | 0.4 | 17 | 15 | 7 | 4 | 0 | 2 | 10 |

**Supplemental Table 2: Characteristics of children ages ≥ with CHD associated with any neurodevelopmental services**

|  |  |  |
| --- | --- | --- |
|  |  | **Receipt of specific neurodevelopmental services****by unique individuals, n (%)** |
| **Characteristic** | **Any Encounter***1***n (%)** | **No Encounter** **n (%)**  | **p-value***2* | **Developmental Testing** | **Psychological Testing** | **Neuropsychological Testing** | **Mental Health Assessment** | **Mental Health Intervention** | **Health and Behavior Assessment** | **Health and Behavior Intervention** |
| Total population (n=503) | 136(27%) | 367(73%) |  | 7(1%) | 49(10%) | 34(7%) | 67(13%) | 66(13%) | 9(2%) | 7(1%) |
| Sex |  |  |  |  |  |  |  |  |  |  |
|     F | 54 (25%) | 162(75%) |  | 29(13%) | 18(8%) | 14(6%) | 23(11%) | 45(21%) | 56(26%) | 5(2%) |
|     M | 82(29%) | 205(71%) |  | 5(2%) | 31(11%) | 20(7%) | 44(15%) | 36(13%) | 4(1%) | 2(1%) |
| Childhood Opportunity Index quintile4 |  |  |  |  |  |  |  |  |  |  |
|     Very Low | 39(32%) | 82(68%) |  | 3(2%) | 16(13%) | 8(7%) | 13(11%) | 16(13%) | 2(2%) | 2(2%) |
|     Low | 26(25%) | 76(75%) |  | 1(1%) | 12(12%) | 3(3%) | 14(14%) | 13(13%) | 1(1%) | 1(1%) |
|     Moderate | 25(27%) | 66(73%) |  | 1(1%) | 11(12%) | 10(11%) | 12(13%) | 7(8%) | 1(1%) | 1(1%) |
|     High | 19(20%) | 77(80%) |  | 0(0%) | 5(5%) | 4(4%) | 14(15%) | 12(13%) | 0(0%) | 0(0%) |
|     Very High | 27(29%) | 66(71%) |  | 2(2%) | 5(5%) | 9(10%) | 14(15%) | 18(19%) | 5(5%) | 3(3%) |
| Rurality |  |  |  |  |  |  |  |  |  |  |
|     Rural | 84(25%) | 248(75%) |  | 5(2%) | 30(9%) | 18(5%) | 40(12%) | 41(12%) | 6(2%) | 6(2%) |
|     Urban | 52(30%) | 119(70%) |  | 2(1%) | 19(11%) | 16(9%) | 27(16%) | 25(15%) | 3(2%) | 1(1%) |
| Insurance |  |  |  |  |  |  |  |  |  |  |
|     Commercial5 | 13 (38%) | 21 (63%) |  | 0 | 5(13%) | 2(6%) | 8(25%) | 8(25%) | 2(6%) | 2(6%) |
|     Medicaid | 83 (30%) | 192 (70%) |  | 7(3%) | 41(15%) | 21(8%) | 34(12%) | 26(9%) | 4(1%) | 3(1%) |
| CHD Diagnosis |  |  |  |  |  |  |  |  |  |  |
| Single ventricle with arch obstruction | 51(30%) | 120(70%) |  | 3(2%) | 15(9%) | 13(8%) | 24(14%) | 26(15%) | 5(3%) | 4(2%) |
| Single ventricle without arch obstruction | 76(27%) | 210(73%) |  | 3(1%) | 32(11%) | 18(6%) | 38(13%) | 33(12%) | 4(1%) | 3(1%) |
| Two ventricle with arch obstruction | 3(20%) | 12(80%) |  | 0(0%) | 1(7%) | 1(7%) | 1(7%) | 3(20%) | 0(0%) | 0(0%) |
| Two ventricle without arch obstruction | 6(19%) | 25(81%) |  | 1(3%) | 1(3%) | 2(6%) | 4(13%) | 4(13%) | 0(0%) | 0(0%) |
| Distance from care centers |  |  |  |  |  |  |  |  |  |  |
| Less than 100 km from nearest regional pediatric center (Bangor, Portland, Boston) | 121(27%) | 326(73%) | >0.9 | 7 | 59 | 59 | 7 | 4 | 31 | 45 |
| Less than 100 km from nearest surgical center (Portland, Boston) | 77(27%) | 213(73%) | 0.8 | 6 | 30 | 38 | 5 | 3 | 17 | 27 |
| *1* n (%); Median (IQR) |
| *2* Pearson's Chi-squared test; |
| *3* n (%)4 Childhood opportunity index v. 2.0, normed by state.5 Includes 41 children with both Medicaid and Commercial insurance |