Supplementary Materials

**Supplemental Table 1: Characteristics of children ages 0-5 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=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 | | | | | | | | | | |