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A Family-centered Brain-Computer Interface Clinical Research Program for Children with Severe Disabilities

Kirton A[1,2*], Rowley D[3], Kelly D[1], Jadavji Z[1], Zewdie E[2], Barnfather A[3], Wieler A[3], Romanow N[1], Floreani E[2], Robu I[3], Keough JRG[2], Irvine B[4], Minhas A[2], Kim VSH[2], Comaduran-Marquez D[1], Kinney-Lang E[4]

[1]*Department of Pediatrics, University of Calgary, Canada;* [2]*Department of Clinical Neurosciences, University of Calgary, Canada;* [3]*Alberta Health Services, Calgary, Canada;* [4]*Department of Biomedical Engineering, University of Calgary, Canada*

28 Oki Drive, Calgary, AB, Canada, T3B 6A8. E-mail: adam.kirton@ahs.ca

Introduction: Cerebral palsy is the largest contributor to the global burden of severe neurological impairment. Brain-computer interfaces (BCIs) are a potential solution, but pediatric populations have been neglected from research and progress [1]. We established a family-centered pediatric BCI clinical research program (BCI4kids) to enable children with severe motor impairments to realize new participation in life.

Materials, Methods and Results: Children and their families were identified within a population-based, tertiary-care children's hospital. Criteria included: 1) age 4-18 years, 2) severe physical disability (non-ambulatory, minimal hand use, nonverbal), and 3) estimated grade 1 cognitive capacity. After initial screening for BCI competency, participants attended regular sessions, attempting commercially available and customized non-invasive BCI systems to operate a suite of applications (e.g., gaming, device control, art, communication). Outcome measures included personalized goal achievement (COPM), family engagement and experience (MPOC-20, PRIME-P), and technology efficacy and usability. Over 5 years, we have enrolled 34 participants (median 12.4 years, range 3-18, 53% male, 24 distinct etiologies). BCI systems and training were well tolerated with no serious adverse events. All but one participant demonstrated the ability to perform BCI tasks. More than 940 hours of participation have occurred across >820 sessions. Mental imagery-based tasks were the most successful, while other paradigms (P300, SSVEP) had lower efficacy and tolerability. Popular applications included painting, cooking, environment control, internet access, and video games. Six children chose and accomplished power mobility goals (Figure 1). Successful translation of BCI systems into home environments was demonstrated with 11 families, totaling >460 sessions. Families reported a major positive impact and their high engagement informed program development. The program has been implemented in the provincial healthcare system, with increasing referrals and waitlists.

Figure 1: An 11-year-old uses BCI to drive his wheelchair using a power trainer.

Conclusions: Family-centered clinical BCI programs can allow children with severe disabilities to achieve novel, personal goals that they previously considered impossible. Future directions include expansion to other hospital sites in Canada and additional resources to support home and community-based participation.

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[1] Kirton A. Trapped Children: A Moral Imperative to Advance Pediatric Brain Computer Interfaces. JAMA Peds 2023 Jun 20. doi: 10.1001/jamapediatrics.2023.1744.

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