**INTRODUCTION**

Surgical and perioperative advances in the field of congenital heart disease (CHD) have increased survival of these patients. A growing body of evidence affirms the presence of neurodevelopmental morbidity in survivors of CHD (Gerdes & Flynn, 2010). By the age of five, neuromotor sequelae are present in approximately 50% of children with CHD (Gerdes & Flynn, 2010). The disabilities range from those that are barely noticeable, to severe dysfunction that severely impacts quality of life (Gerdes & Flynn, 2010). In addition, the prevalence of disability increases with increasing complexity of CHD.

Disability has been recognized in the following areas:
- Intelligence
- Language (development, expressive, and receptive)
- Executive function
- Fine Motor skills
- Gross Motor skills
- Attention & Behavioral problems (internalizing or externalizing behaviors)

**LITERATURE SYNTHESIS**

A literature search was conducted to explore the efficacy of early developmental intervention in improving developmental outcomes. An exhaustive search was performed in Cochrane Library, CINAHL, PubMed, PsycINFO, and PsycINFO. Synthesis of the evidence revealed:

Early developmental intervention improves outcomes in the following areas:
- Intelligence & academic success
- Motor
- Language
- Personal-Social skills

Inexperienced programs in CHD:
- Began intervention before six months of age
- Included parental interaction as a key component of therapy
- Interventions are long-term, throughout infancy & toddlerhood

**RESULTS**

**Acquisition of Services**
- 50% Not receiving any therapies before CCriB
- 62% Ordered additional therapies at CCriB
- 100% of those needing therapy, receiving at least 1 therapy at follow-up

**Therapies Before vs. Therapies Ordered**
The mean number of therapies before the visit was 0.38 (sd-7.4), and the mean number of therapies ordered after the visit was 2.00 (sd-1.41). A significant increase from before the CCriB visit to after the visit was found (t(7)=-2.20, p<.05).

**Therapies Before vs. Therapies Receiving at Follow-Up**
The mean number of therapies before the visit was 0.38 (sd-7.4), and the mean number of therapies ordered after the visit was 1.25 (sd-1.04). A significant increase from before the CCriB visit to after the visit was found (t(7)=-2.20, p<.05).

**Barriers to Services**
- 16 therapies ordered, 10 received, 60% acquisition
- Distance/transportation issues
- 25% unable to get services due to A/EIP denial for additional therapies
- 1 needed to get prescription from PCC, rather than specialist
- Lack of parental follow-up

**CONCLUSIONS**

- Local Impact: CCriB Program at PCH
  - Presented CCriB Program to parents at Cardiac Day at the Zoo
  - PAUs Grant for purchase of equipment
  - Designated clinic in Heart Center for CCriB Program
- Increased awareness of importance of developmental needs
- Political Impact: Care Coordination for CSHCN
- Developmental care in this population becoming standard of care
- Increased awareness among primary care providers

**REFERENCES**


**INTERVENTION**

**Cardiology Critical Brain Development Program (CCriB)**

**Objectives**
- Increase acquisition of developmental therapies
- Aid children in acquiring these services as early as possible, goal being by 6 months of age
- Educate parents on the risk of developmental delay, as their participation is essential to the child’s success
- Program Structure:
  - Provides periodic developmental evaluation & monitoring for children with complex CHD
  - Minimum yearly evaluation from birth to age 5 by a developmental pediatrician to identify developmental delay and refer for therapy as needed.
  - Parental education via handouts and one-on-one instruction with developmental pediatrician

**METHODS**

**Primary Aim:**
1. Assess CCriB Program effectiveness in improving acquisition of developmental services
2. Assess barriers to acquiring developmental services for children

**Design**
Prospective chart review & telephone interview of parents

**Population**
Single-ventricle CHD s/p stage 2 or 3 palliation AND <4 years of age (48 mo)

**Data Collection**
<table>
<thead>
<tr>
<th>Demographics</th>
<th>Presence of developmental services</th>
<th>Barriers to Care</th>
<th>Barriers to care: (follow-up phone call)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Initiation of services prior to CCriB visit</td>
<td>Time from referral to appointment</td>
<td>Has the child received services and therapies they were ordered? Why not?</td>
</tr>
<tr>
<td>Cardiac Diagnosis</td>
<td>Initiation of services after CCriB visit</td>
<td>Attendance</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Which intervention services were initiated?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary language spoken at home</td>
<td>Age at acquisition of developmental therapies</td>
<td></td>
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