

Are children with heart conditions receiving the rehabilitation services they NEED?

childhood
disability
LINK



Summary

The purpose of this study was to describe the educational and rehabilitation services being provided to young children with heart conditions who had had an open-heart surgery. Parents of these children were surveyed by phone. Most children were in grade one, two or three at the time of the survey. Results of the questionnaire indicated that of the 60 children, 22% were receiving educational support services, which primarily included supplemental tutoring. An additional 17% of parents felt their children needed educational supports but were not getting them. Rehabilitation services were being provided to 23%, with an additional 20% of parents saying that their child needed services but weren't receiving any. Parents' perceptions of the barriers to receiving educational and rehabilitation services included lack of referral, waiting time, costs and access. More than half of children with developmental delays, as identified on our 5-year follow-up assessments, were not receiving the appropriate rehabilitation services at school age.

What practitioners should know

Children with congenital heart defects are at high risk for developmental delays. Nonetheless, many are not receiving adequate educational and rehabilitation service supports at school-age. Medical practitioners (cardiologists, pediatricians) who monitor the cardiac status, growth and development of children with congenital heart defects that require surgical repair should also carefully monitor the developmental and academic progress of these children who are at risk. If there are possible concerns identified, the child should be referred to the appropriate professionals to evaluate and intervene as needed, in order to minimize disability and school failure. A developmental screening process and the availability of a resource person for information and referral should be considered as part of current service delivery to children followed with congenital heart disease.

Reference

Glass, H., Bowman, C., Chau, V., Moosa, A., Hersh, A., Campbell, A., et al. (2011). Infection and white matter injury in infants with congenital cardiac disease. *Cardiology in the young*, 21, 562-571.