

**Increasing Genetic Referrals for Children Identified through EHDI –
An Action Guide for Providers serving children with or at risk for hearing loss**

INTRODUCTION

The Region 4 Genetics Collaborative strives to improve outcomes for children who have genetic conditions. With research showing that 50% of hearing loss in infants is genetics-related, the Early Hearing Detection and Intervention (EHDI) Follow-up Workgroup was established and charged with improving access to genetic services for families whose children have been diagnosed with hearing loss through universal newborn hearing screening (UNHS).

The workgroup engaged in a series of activities to learn how state EHDI and genetics programs in the region interact, examine the EHDI follow-up system to identify encounters that provide opportunities for offering a genetic referral, and explore materials for educating parents and professionals about the importance of a genetic assessment for children with diagnosed hearing loss. The workgroup developed this guide to assist providers in increasing genetic referrals for children in the EHDI follow-up system. The guide assists providers by identifying encounters which typically occur in the course of the follow-up services system with either the family or with other providers which present an opportunity for making the genetic referral. The guide also includes tools to facilitate getting families appropriately referred for genetic services.

HOW TO USE THIS ACTION GUIDE

This Provider Action Guide was designed to help providers assist families who have children with permanent hearing loss in obtaining genetic services. The Action Guide is organized into four sections:

Section 1: Guidelines & Logic Model. *This section includes Region 4's recommended guidelines for increasing genetic referrals and the logic model showing including assumptions, outcomes and strategies that will result in increased referral. This information describes, and provides support for the Region 4 Genetics Collaborative position on increasing access to genetic services for children in the EHDI system.*

Section 2: Patient Encounters – opportunities for genetic referrals. *This section is organized by the continuum of follow up services that present opportunities to make or recommend the genetic referral, inquire about whether or not a referral has been made, or encourage another provider working with the family to*

facilitate access to genetic services. This section helps the provider identify encounters which may provide an opportunity for a genetic referral to be made.

Section 3: Strategies for Providers. This section is organized by provider type. For each type of provider, a list of strategies specific to the provider working with families who have children in the EHDI follow-up system are suggested to increase referrals to genetic services. A provider may choose to implement one or as many as are appropriate. This section helps providers select and implement specific strategies to increase referrals to genetic services.

Section 4: Tools. This section includes tools to help increase genetic referrals. Providers may choose to use the tools as presented or adapt as appropriate.

REGION 4 WELCOMES YOUR INPUT

We hope that this action guide proves to be a useful tool for providers in increasing referrals for genetic services for families receiving services in the EHDI system. We welcome suggestions for adding encounters, provider strategies, or other feedback to improve its utility. Please contact us via email at region4@region4genetics.