Providing resources and support to families affected by birth anomalies: A collaborative model between state public health and an established peer support program

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TOPIC/TARGET AUDIENCE: We provide a description of the partnership between Oregon's Birth Anomalies Surveillance System and the Oregon Family to Family Health Information Center. This includes rationale for the partnership, program activities, and description of the outreach, education, and referral supports for families. This presentation targets public health professionals who are interested in areas such as maternal and child health, statewide peer support programs, and health care and resource navigation.

ABSTRACT: The Oregon Birth Anomalies Surveillance System (BASS) is funded by the Centers for Disease Control and Prevention to conduct surveillance, promote prevention strategies, and to utilize data in a way that can aid individuals and families in obtaining services. The BASS is unable to contact affected families directly to link them to resources. To fulfill grant requirements and the public health imperative of data to action, the BASS contracted with the Oregon Family to Family Health Information Center (OR F2F HIC) of the Oregon Center for Children and Youth with Special Health Care Needs to provide outreach, education, and referral support for families affected by birth anomalies (BAs).

OR F2F HIC, with the BASS, is developing a detailed webpage with resource sheets on all 50 BAs tracked, launching in summer 2017. The BASS and its community and public health partners will link to this webpage. OR F2F HIC provides parent peer educators statewide and a call line for support and navigation assistance including referrals and toolkits. This collaborative model conserves resources by leveraging an existing statewide family support program to link families with resources without compromising privacy and confidentiality of the BASS data. Evaluation is ongoing.

OBJECTIVE(S): Describe how this model leverages partnership with an existing program to overcome legislative and infrastructure barriers in assisting families affected by BAs. Identify the centralized information and support contact point for Oregon families with BAs and the types of assistance that they provide.

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