

Sarah Bobo-Horton provided this background on the development of the clinics.

Background related to the history with the clinics:

Prior to funding provided by MDCH in 1999 to train multidisciplinary teams of healthcare providers in the University of Washington's 4-digit diagnostic code for FAS, most diagnostic services for FAS in Michigan were conducted by a small number of individual doctors or geneticists. The diagnostic process was limited and did little to offer insight about the implications of the disability or provide recommendations for aftercare planning.

The exception was a multidisciplinary group volunteering for the University of Michigan. This team was developed in the 1990's under the impetus of Barb Wybrecht, RN. It consisted of a full cadre of multidisciplinary professionals who volunteered their time one Saturday a month to make assessments and provide recommendations for individuals affected by prenatal exposure to alcohol. Assessments were highly regarded and sought after by individuals throughout the State. The dedication of the team members was remarkable and many of the original team members remained a part of the clinic until the recent change in leadership this past year.

Due to the complexity of issues which result from prenatal exposure to alcohol, advocates in the FASD community have long been vocal about the need for comprehensive, multidisciplinary diagnostic assessments. The most beneficial information provided by these assessments is often viewed as the interpretation of psychological testing in light of the implications of prenatal alcohol exposure. Without the context and appropriate expertise, psychological testing, typically conducted through school systems, was providing limited information to families. In contrast, neuropsychological testing provided by a psychologist knowledgeable about FASD has been described by many as invaluable.

At the time funding was first allocated for FAS activities, advocates from the field expressed their strong desire to establish more comprehensive FAS diagnostic clinics similar to the one in Ann Arbor. Bill Holland, public health consultant at MDCH was providing oversight for the FAS funds at the time the sites for the Michigan FAS Diagnostic Clinics were selected. The original clinic teams were from:

- University of Michigan in Ann Arbor
- Mott Children's Health Center in Flint
- Spectrum Health in Grand Rapids
- Marquette General Hospital in Marquette
- Children's Trauma Assessment Center in Kalamazoo

Although I was not directly involved with the selection of the clinics who received funding to go to the University of Washington for training in the FAS 4-digit diagnostic code, to the best of my knowledge, the groups selected were already providing some form of FAS evaluations and were receptive and ready to receive training on a multidisciplinary approach to diagnosis.

After the clinics teams were trained, a state workgroup was formed to promote collaboration with diagnostic teams and key advocates in the FAS field. Original workgroup members were:

- Bill Holland, MDCH
- Barb Wybrecht, Independent Consultant
- Sarah Horton Bobo, Kent County Health Department
- Karen Twa, Marquette General
- Marie Heys, UM
- Connie Black-Pond, CTAC
- Patricia Gushman, Mott
- Marty Manty, Catholic Human Services, Traverse City

Background of the establishment of the FAS Diagnostic Clinic at Spectrum Health:

Prior to funding from MDCH in 1999, FAS diagnostic evaluations in the Grand Rapids area were primarily conducted by a PhD, Geneticist at Butterworth Hospital (now Spectrum Health).

In 1997, I got involved with a Grand Rapids area FAS parent support group that had recently formed. Through this group, I learned about many of the challenges and struggles families raising children with FASD encountered. Many families were expressing dissatisfaction with the limited information and lack of clinical recommendations they received from evaluations provided through the Genetic Services Department. These families petitioned top administrators at Spectrum Health to develop a multidisciplinary FAS diagnostic clinic.

This coincided with the funding made available through MDCH and as a result, a full multidisciplinary team was established under Spectrum's DeVos Children's Hospital. Given the limited amount of funding available, staff members had very little time allocated to the clinic. Some staff members expressed concern with not being able to spend adequate time to meet families' needs and as a result it was decided to return diagnostic evaluations to the Genetic Services Department. Families again expressed their concern over this arrangement with administrators at Spectrum Health. It was at that time, that Barbara Wybrecht was hired to work for Genetic Services on the FAS evaluations.

Barb's involvement with the clinic still did not create a full multidisciplinary team but parents knew that she would do whatever she could to ensure that individuals received as much of a comprehensive assessment as possible. Now that Barb has retired from the clinic in Grand Rapids, concerns are again being vocalized.