Appendix 12.3

Suggested List of Data Variables to Collect for Prenatally Diagnosed Defects
(Note: Items in italics can be collected based on a program’s needs.)

12.3.1 Prenatal Information

Date of last menstrual period
*Estimated date of delivery*
Date and gestational age of first ultrasound for dating purposes, regardless of whether a defect was diagnosed or suspected (record the earliest ultrasound available if there is no information about the very first ultrasound done)
Date and result of prenatal diagnostic tests (amniocentesis, CVS, ultrasound, fetal echo, etc.)
Date of prenatal diagnoses – final confirmation if multiple tests or procedures
Gestational age at confirmation of prenatal diagnoses
Fetal sex
Plurality (single, multiple gestation; if multiple, number of fetuses)
*Date of first prenatal visit*
*Date of initial screening*
*Gestational age at screening*
*Prenatal screening provider*
*Screening tests administered*
*Screening test findings*
*Prenatal diagnosis provider(s)*

12.3.2 Outcome Information

Pregnancy outcome (if known from prenatal record)
   Live birth, stillbirth, spontaneous abortion, elective termination, unknown
Date of pregnancy outcome
Place of pregnancy outcome
Gestational age at outcome
Date and result of any post-delivery evaluation of defects
   Cytogenetic analyses performed (normal and abnormal)
   Pathologic or autopsy examination of the fetus or infant (if a live birth)
   Postnatal diagnostic tests and procedures performed (if a live birth)
Final diagnoses
*Infant’s name if a live birth*
*Location of outcome*
*Delivery and post-delivery care providers*
12.3.3 Demographic Information

Mother’s data:
   Age
   Race
   Ethnicity
   Residence at time of prenatal diagnosis or at delivery: street address, city, county, state, zip code, census tract (exactly which items are collected will depend on the program’s needs)
   Name
   Date of birth
   Education

Father’s data:
   Age
   Race
   Ethnicity
   Name
   Date of birth
   Education