Since the Convention on the Rights of Persons with Disabilities came into force (2008), the drive towards more disability-inclusive education is gaining momentum. Unfortunately, the data needed to develop, implement, monitor and evaluate inclusive policies is often lacking. Fortunately, tools to collect those data have been developed to fill that gap, and they are growing in use. Such data can come from a variety of different sources, depending on the purpose of data collection.

Survey data. Currently, household survey data is used to monitor children’s school attendance and achievement rates, as well as to examine the factors correlated with being out of school. Recently, UNICEF – working with the United Nation’s Washington Group on Disability Statistics – has developed a Child Functioning Module (CFM) that can identify most children (aged 2–17) with disabilities. 70 countries are now slated to use CFM, which has been incorporated into the upcoming round of UNICEF’s Multiple Income Cluster Survey (MICS).

An important feature of the CFM is that it is designed to be included in already existing surveys. It does not require a special survey, but can use the existing survey infrastructure. As long as the CFM is included in surveys designed to collect the Sustainable Development Goals indicators, they can all be disaggregated by disability status with only marginal expense.

Administrative data. Educational management information systems (EMIS) contain school administrative data used to monitor student attendance, behavior and progress, and to budget and plan for school activities. But, too often EMIS contain poor, or even no, data on children with disabilities, rendering these children’s experiences invisible and hampering efforts to promote inclusion. That is now changing. UNICEF has designed a template for identifying children with disabilities that takes the same basic approach as the CFM. It does not mention the word “disability,” which can be stigmatizing and misunderstood, nor does it require teachers to attempt medical diagnoses for which they are unqualified, and which are rarely helpful for educational planning.

Instead, the CFM focuses on the types of difficulties a child has in the classroom – seeing, hearing, moving, communicating, etc. This approach has been incorporated into the UNESCO-led OpenEMIS
initiative and is currently being used by at least 10 countries. But to really address inclusion, schools must also collect data on the school environment. Disability is a result of the interaction between an individual’s functional limitations and barriers in the environment. To achieve inclusion, it is the environment that must be changed – the removal of not just physical barriers, but communication, attitudinal, and institutional ones as well. It is important for EMIS to also collect information on school facilities, materials, and human resources, such as teacher training on inclusion. UNICEF has a webinar and associated technical workbook providing guidance on this.

Fiji is a good example of a country collecting high-quality data on both children with disabilities and the school environment. Whereas in many countries the EMIS collect only aggregate data at the classroom level, the Fiji system collects student-level data, so individual students can be tracked. And, whereas many schools collect data only at the beginning of the year – before teachers know their students well enough to identify those with difficulties – the Fiji system is electronic and can be updated continually throughout the year. Teachers’ ability to properly identify children using the Fiji Education Management Information System (FEMIS) tool was validated by a field study.

UNICEF and the Washington Group are in the final stages of testing a question set that collects data from parents on barriers to education, which can be used as a module in household surveys as another source of environmental data.

Qualitative data. Survey data tell us who are out of school. EMIS can tell us how students are doing, school budgeting needs, and schools’ progress in removing barriers to education. But those data cannot give us the “how and why” details of students’, teachers’, and parents’ lives. For that information, which is essential for developing programmes, teacher training, and curricula, it is important to collect qualitative data.

Whatever the data being analysed, however, it is important to include people with disabilities at every stage – design, collection, and analysis – because only they have first-hand experiences of what it means to live with a disability within the country context. As the oft said – but never too often said – saying goes, “nothing about us, without us.”