

Data Use Guidelines

General Information

Use data carefully. Use the language that accompanies the data exactly as it is written. It is tempting to make the information more user-friendly, or to change it just a little to fit with a story about a family or a piece of legislation. However, researchers warn us that changing the language or the numbers to fit a particular idea ruins the reliability of the data and the research. When in doubt, contact the source of the data (which is usually listed), or the Family Voices staff research expert, Nora Wells.

Using Data With The Media

Be careful. Reporters often have developed a story idea even before talking with you, so, the questions they ask might have a "pitch" or a "slant." For example, a reporter might have been told that many kids with special health care needs cannot receive physical therapy/PT services. The reporter believes it's because there are not enough PTs to go around, and most of her/his questions might revolve around that idea. However, you know the real reason for the scarcity of PTs is that Medicaid and private insurance in your state: 1) Don't pay PT providers adequately; 2) Or only cover PT when it's needed after an accident or surgery, not for kids with disabilities. Before you talk to the reporter, get the facts about PT services: 1) Numbers of PTs in the state and locations; 2) Private insurance and Medicaid rates for PT; 3) What benefits packages do and do not cover. Get facts from a reliable source (state PT association, state insurance office, Medicaid, for example). Share your information with the reporter. With good facts and family stories, a reporter will more likely write a story that could help raise PT reimbursement rates or improve Medicaid and private insurance benefits packages.

Using Data to Backup Family Stories

One of the best ways to use data is to combine it with a real-life situation. For example, if the Medicaid rates for dentists are so low that families cannot find dentists to treat their children, you might: 1) Find several families and dentists willing to talk to the press and policymakers; 2) Get information about the Medicaid dental payment rate from the state Medicaid agency and the state dental association; 3) Use the Fact Sheet data about the numbers of children in the state who have special health care needs to explain that MANY (because you know it's not ALL) of these children need specialized care from dentists who are adequately paid. In this case, you have advocacy backed up by science (research and data) to make your case.

Guidelines

1. Quote any statements or phrases DIRECTLY from any of the Family Survey reports. These reports are listed below and can be sent from the national office or found on the Family Voices website. Please acknowledge from where the information comes.
2. Do NOT rephrase any of the material in the reports. Just quote directly. Replacing even one word from a research document can change the meaning of the data in ways never intended.
3. Do NOT add your own ideas to the findings. Even if the research seems to support a point you want to make, do not be tempted to just add a word or two. Those kinds of changes can damage the data.

Examples of What Not to Do

Here are examples of how two of the findings were combined and used in ways that reflect neither what families really said or what the Family Survey reported. We want to avoid using data in this way.

What the findings in the Family Survey Report really said:

- "Nearly two thirds (60%) of the mothers reported that they had reduced their hours of employment and/or stopped working altogether because of their child's health conditions."
- "Families whose child's primary plan was paid by Medicaid were more satisfied with their plan than families in private health plans. "

How the above findings were used and interpreted in ways not actually reported:

- "A study recently completed by Brandeis University and Family Voices documents that Medicaid is the best benefit package for children with special health care needs, and that 68% of the studied families had to cut back on their employment or quit working altogether in order to obtain and maintain the coverage their children rely on to stay alive and healthy."
- "In a recent family survey of 20 states, 64% of families with special needs children report they are turning down jobs, turning down raises, turning down overtime, and are unable to save money for the future of their children and family - so that they can stay in the income bracket that qualifies their child for SSI or Medicaid."