Data-Informed Stakeholders: Building Family Capacity to Understand and Use EI/ECSE Program Data

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Families as Systems-Level Decision-Makers

"Family engagement is the systematic inclusion of families in activities and programs that promote children's development, learning, and wellness, including in the planning, development, and evaluation of such activities, programs, and systems."

—U.S. Department of Health and Human Services & U.S. Department of Education, 2016, p. 1

Family Engagement in Data Use

* **Child level—**Families partner with professionals to make decisions that set directions for their children based on data, including partnering to:
  - Collect and use assessment data.
  - Set goals and identify the kinds of services and supports that will be provided.
  - Determine the impact or effectiveness of services.
* **Systems level—**Family leaders use program data to advise the state's IDEA lead agency on EI and ECSE policies, procedures, and improvement efforts.

Strategies for Improving Data Literacy in Family Leaders

Provide an Orientation to Program and Policy Data

Family leaders can participate in more meaningful conversations at the systems level with a better understanding of the types of data EI and ECSE programs are collecting. Family leaders need to know:

* How data are used as information for decision-making.
* Federal and state IDEA data reporting requirements.
* The State Systemic Improvement Plan (SSIP) process and the role of stakeholders in that process.
* Data privacy and confidentiality considerations.
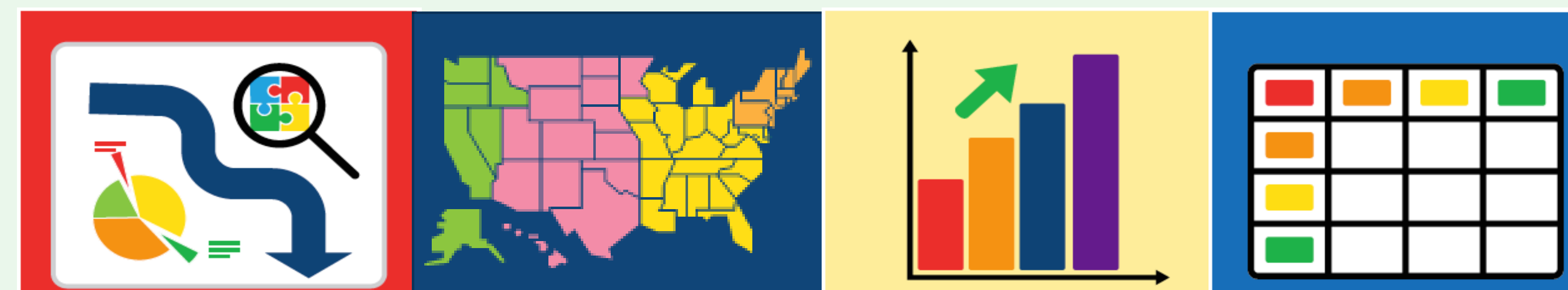* How and why IDEA programs link data with other programs and K-12 data.

Connect Personal Uses of Data to Programmatic Uses

Family leaders need opportunities to see how the data about their own children are connected to data on services and outcomes across the system—for example, how the data on the services in their Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP) are contributing to the data on the total amount of services provided by the program statewide.

Share Data in Engaging, Comprehensible, and Meaningful Ways

Good data visualization helps family leaders comprehend information quickly and identify relationships, patterns, and trends. Sharing data in a way that communicates a story makes the data more meaningful.

Check out the DaSy Center's Data Visualization Toolkit at http://dasycenter.org/data-visualization-toolkit/
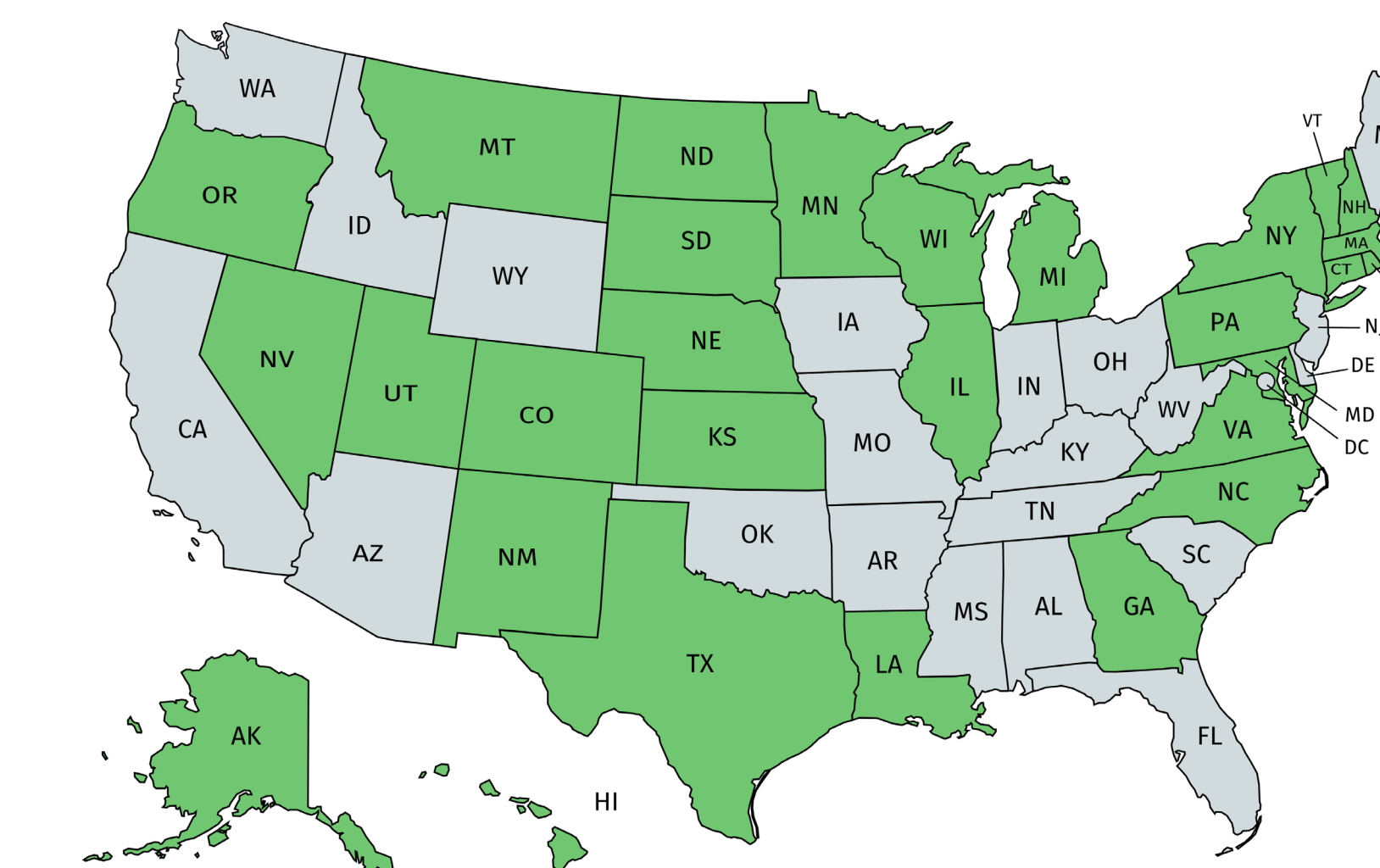
Help Families Ask Good Questions About Data

Family leaders need to be able to interpret data and draw conclusions. To do this, they need to be able to ask good questions about data, such as:

* How and when were the data collected?
* How do we know the data are valid (or accurate)?
* Are there trends or patterns in the data and, if so, what are they telling us?

DaSy Family Data Institutes

In 2015 and 2016, family leaders, parent center staff, and Part C/Part B 619 state lead agency staff from 29 states participated in topical meetings aimed at preparing family leaders to engage in conversations about IDEA program data in their states.

Family Data Institute, October 2016 (Louisville, KY)

Connections to DEC Recommended Practices

* **Family, 2:** Practitioners provide the family with up-to-date, comprehensive, and unbiased information in a way that the family can understand and use to make informed choices and decisions.
* **Family, 10:** Practitioners inform families about leadership and advocacy skill-building opportunities and encourage those who are interested to participate.
* **Leadership, 12:** Leaders collaborate with stakeholders to collect and use data for program management and continuous program improvement and to examine the effectiveness of services and supports in improving child and family outcomes.