



## PURPOSE OF THE BRIEF

This brief will present key issues related to using data for decision making within organizations supporting people with intellectual and developmental disabilities (I/DD). The word data refers to information that is collected in order to develop, implement, and assess positive behavior support (PBS). This brief will also discuss common challenges that occur when data are used to support people with I/DD. Suggestions for addressing these challenges and recommendations for using data for decision making will be shared.

## INTRODUCTION

Data are a key part of PBS because the information gathered is used to inform how well interventions are implemented and whether PBS is making a positive change. Data are used to monitor and measure progress in ways that are objective (Darren, et al, 2018). The references below provide examples of research and tools that support the use of data to guide PBS implementation.

It is important to understand the kinds of data that can be collected and how these data can be used for decision making. Data help us understand how satisfied people are with PBS and whether important quality of life changes occur for the people receiving supports. These data are used in a number of different ways so that teams can make informed decisions.

Research clearly supports the use of data for decision making when supporting people with I/DD. However, there are a number of challenges that organizations and teams face when collecting and analyzing data. For instance, some people assume that collecting data is too difficult and time intensive. A team may not understand the meaning of the data collected or how to use it on a regular basis to guide decisions.

It is important for organizations implementing PBS for persons with I/DD to collect and analyze data in an effective manner. The following sections of this brief will present the key elements for data collection and discuss the challenges that organizations face when using a data-based approach.

## KEY ELEMENTS

Data-based decision-making is a process of using data to guide decisions. There are two elements to effective data-based decision-making:

- (1) Following a four-step problem-solving process**
- (2) Reviewing fidelity and impact data**

A four-step problem-solving process starts with teams analyzing a range of data to identify areas of need. Teams then set measurable goals. Goal setting allows teams to work together to find solutions and create an action plan. The team then monitors the plan to determine if it is being implemented as intended and the impact on outcomes. See the Team Initiated

Problem Solving Fidelity Checklist in the Helpful Resource section for more details.

Data reviews start with determining if PBS efforts are being implemented as intended (fidelity). It is important to be able to say “Yes, we are doing what we said we would do” before looking into the impact of PBS efforts on valued outcomes. Fidelity measures include tools and processes to evaluate organization level and staff level implementation of PBS. Organization level tools are collected quarterly or annually (examples of these tools are in the Helpful Resource section). Staff implementation can be measured weekly by observing staff implementation (e.g., positive interactions, following activity schedules).

Once fidelity has been determined, teams review data to evaluate the impact of PBS on outcomes that are valued by people receiving and providing supports. The multi-tiered PBS logic encourages teams to look at trend data, or patterns, across the organization and a person's individual data.

Organization-level measures help teams analyze patterns across people supported and across staff members. Types of organization-level data include staff turnover, staff retention, and overall satisfaction of people receiving supports as well as the viewpoints of other stakeholders (e.g., families or guardians). Organizations that work on improving cultural responsiveness measure the diversity of staff members and recruitment and retention patterns of culturally diverse staff. Other organization-level data include quality of life measures, overall incident report data, use of restrictive procedures over time, injuries due to challenging behavior, and the number of people in need of intensive PBS plans.

Individual-level measures are used to analyze data in order to support one person with a PBS plan who is supported by a team of individuals who knows that person well. Measuring quality of life for people being supported and for their staff on an ongoing basis helps make sure that changes can be made

as soon as possible when improvements are needed. Teams need measures that assess the many different indicators of quality of life. Examples of these indicators include measures of health and wellness, inclusion in the community, and feelings of connectedness with loved ones. Other types of measures focus on decreases in challenging behavior and on the positive changes that are made to help people communicate using alternative responses that replace challenging behavior. Teams also measure the goodness of fit of the interventions that are part of a PBS plan. Goodness of fit includes assessing how well the interventions that are chosen fit the values, resources, and skills of the people who are implementing the PBS plan.

It is helpful to develop an evaluation plan that provides details about how and when to collect data given the many layers of data that can be used by organizations for decision making. This plan includes evaluation questions that address both organizational-level and individual-level issues. Sources of data, methods for recording and reporting data, a schedule for review and analysis, and the people responsible for securing each source of data are included in the evaluation plan.

## CHALLENGES AND SOLUTIONS

### CHALLENGE

**Data collection is viewed as cumbersome or time consuming**

### SOLUTION

**Teams can evaluate what data sources they already have access to and how to build in additional data sources to common routines or automated systems**

**Data are collected, but are not synthesized**

**An important aspect of data-based decision making is synthesizing these data in a central location for ease of data analysis. Due to privacy requirements, certain data may need to be de-identified and aggregated**

**Implementation of practices is inconsistent or varies across people and teams**

**On-going measurement of fidelity is important to establish when a practice is being implemented as intended, to monitor maintenance (prevent drifting away from effective implementation), and to provide booster training, when needed**

**Data are only evaluated when things "are going wrong"**

**Positive behavior support as a system requires proactive and preventive (as opposed to reactive) data-based decision-making. Teams should have a regular time scheduled for reviewing and analyzing data. For example, consistent data collection and analysis is needed to ensure a person continues to maintain positive effects from an intervention and for their overall Quality of Life**

## CHALLENGES AND SOLUTIONS (CONTINUED)

### CHALLENGE

Teams have data but are unsure how to analyze or make decisions from it



### SOLUTION

Some data may be best analyzed in aggregated forms. Simple tools (e.g., Microsoft Excel) may be used to create measures such as:

- total count,
- rate,
- central tendency (mean, median, mode), and
- variation or “spread” of scores (e.g., range).

By using simple metrics, teams can sort scores and teams compare and contrast data for trends, such as overtime or across locations/populations.

Metrics can also be displayed in graphic form, which may be particularly helpful for ease of monitoring data changes over time. Visual analysis can be used to determine changes in:

- trend (the direction of a data path),
- level (a change in data on the y-axis (vertical part of the graph), and
- variability (the consistency, or lack thereof, of a data pattern)

## RECOMMENDATIONS

**Use data to inform all aspects of positive behavior support.** Key elements of any positive behavior support framework includes implementation fidelity, valued outcomes, acceptability, satisfaction and quality of life.

**Collect data at all three Tiers of PBS including Tier 1, or universal interventions, Tier 2 for minor challenges, and intensive individualized PBS plans at Tier 3.** Data analysis needs to be conducted on multiple levels including the organizational level, team level, and individual person levels.

**Develop data systems in compliance with federal, state, and local regulations.** This will reduce the chance that data collection efforts will overlap resulting in duplicated measurement systems and improve efficiency.

**A primary goal of implementing PBS for people with I/DD is to provide evidence that any interventions implemented will improve quality of life.** Creating systems to monitor quality of life on an ongoing basis using data for decision making helps organizations assess the cost benefits associated with the PBS framework.

**Develop an evaluation plan to guide the multiple levels of data collection and analysis throughout the organization.**

**Design best practice guidelines for the development, use and analysis of data as part of an international PBS I/DD effort so that these standards can be applied across countries, providences, states and organizations.**

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## CITATION

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