

PERFORMANCE MEASURES DATA FROM YOUTH WITH SPECIAL NEEDS

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WORKSHOP OBJECTIVES

- Identify potential stakeholders to engage in developing survey administration methods appropriate for youth with special needs
- Describe strategies for collecting survey data to ensure comprehension, maximize response and completion rates, reduce social desirability bias in youth responses, and create a positive experience for youth with special needs
- Discuss considerations when obtaining parent consent and youth assent and ensuring privacy

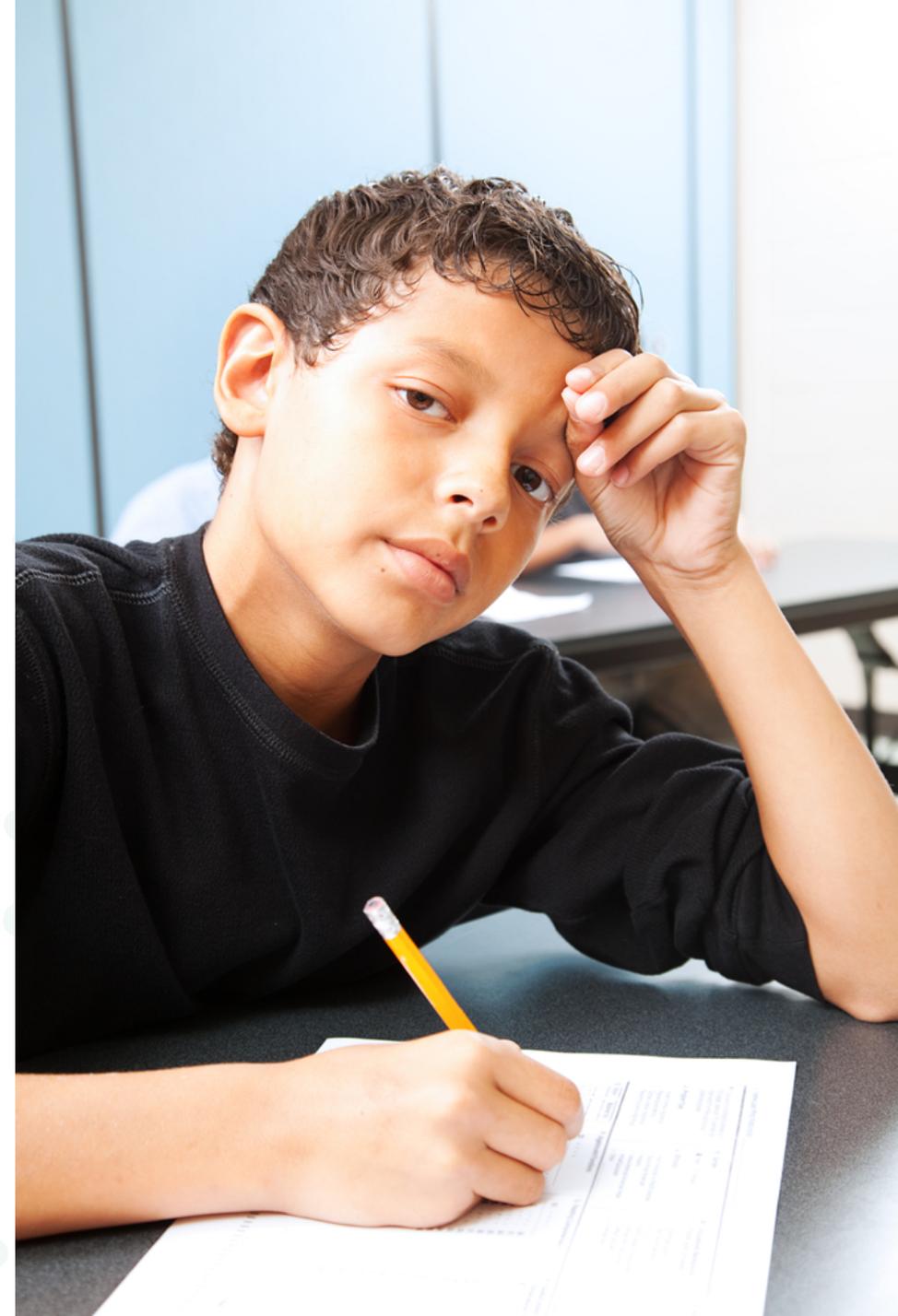
“We were never given any training to collect survey data from youth with special needs.”

Source: Adapted from Bhatnagar & Das (2014)



“The simplest things become a distraction;
my mind starts to wander.”

Source: Hong (2015)



POLL

What are the special needs of youth you serve?

- ADHD
- Intellectual disability
- Autism
- Learning disorder
- Low reading comprehension
- Other developmental delays (specify in chat box)
- Other (specify in chat box)
- More than one type of need (specify in chat box)

18%

of youth have
disabilities
that may affect
survey participation

Source: Zablotsky et al. (2019)



DIVERSITY NEEDS TO BE REPRESENTED IN PERFORMANCE MEASURES DATA COLLECTION



GENERAL ORGANIZATIONAL PROCESSES AND PROCEDURES TO CONSIDER BEFORE ENGAGING IN DATA COLLECTION WITH YOUTH WITH SPECIAL NEEDS

- Will decision-making responsibilities about survey data collection for youth with special needs be centralized or decentralized?
- Who will be responsible for decisions about accommodations?
- Will you use existing staff to support inclusion or use volunteers or staff paid by outside agencies?
- How will you budget for accommodations?

ENGAGING STAKEHOLDERS TO DEVELOP SURVEY METHODS APPROPRIATE FOR YOUTH WITH SPECIAL NEEDS

KEY DECISIONS:



How to identify youth with special needs



Which stakeholders to engage



What inclusion will look like



How to implement



DECIDE HOW TO IDENTIFY YOUTH WITH SPECIAL NEEDS

Determine how many youth will need an accommodation by:

- Reviewing administrative records
- Asking or surveying parents/guardians, counselors, teachers, or caseworkers
- Including questions on the parent consent form



IDENTIFY WHICH STAKEHOLDERS TO ENGAGE

Engage stakeholders to inform your planning

- Parents/guardians
- Youth
- Program graduates
- Partners
- Educational professionals
- Service providers



DETERMINE WHAT INCLUSION IN DATA COLLECTION WILL LOOK LIKE

- Ask stakeholders for assistance.
- Consider cross-training.
- Decide what data collection accommodations are feasible to offer to youth.



DECIDE HOW TO IMPLEMENT ACCOMMODATIONS

Develop a process within your organization to:

- Identify the person(s) responsible for:
 - Reviewing parent consent forms or survey data
 - Selecting those that indicate special needs
- Identify the person(s) responsible for assessing accommodation needs
- Give the person responsible for the assessment the authority to involve others
- Provide resources to make accommodations

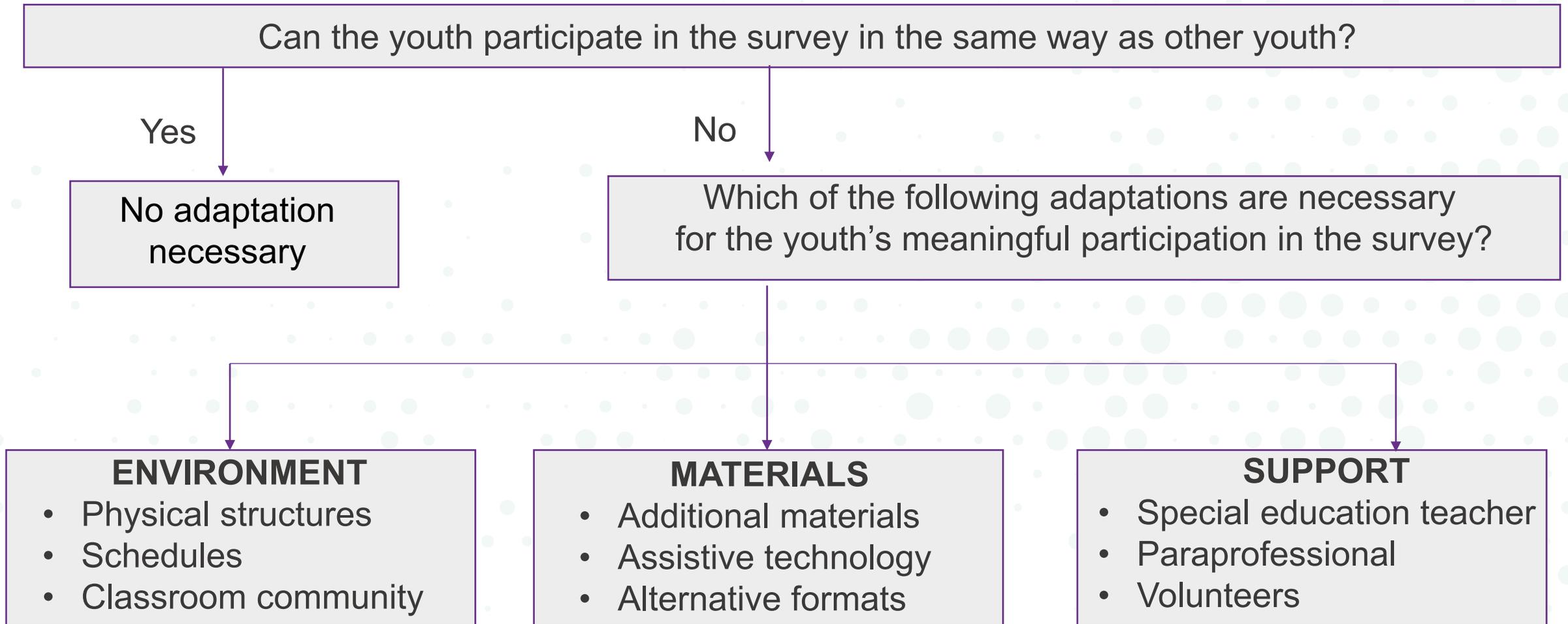


DECIDE HOW TO IMPLEMENT ACCOMMODATIONS

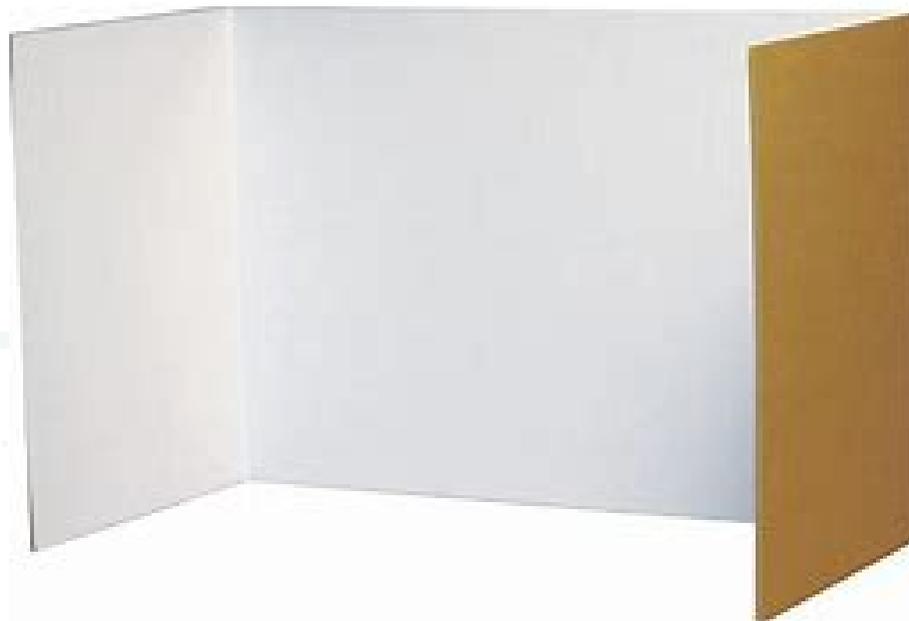
Use the Data Collection Adaptation Flowchart

Handout 1

Data Collection Adaptation Flowchart



DESKTOP PRIVACY SCREEN



Source: Office Supply



DECIDE HOW TO IMPLEMENT ACCOMMODATIONS

Communicate with youth and parents/guardians about individual needs and strategy selection.

INDIVIDUAL ACTIVITY



STRATEGIES FOR COLLECTING SURVEY DATA FROM YOUTH WITH SPECIAL NEEDS

MAXIMIZING RESPONSE AND COMPLETION RATES

The National Longitudinal Transition Study improved the response rate among youth with special needs from 30% in 2012 to 52% in 2013 by expanding from phone surveys to adding a web survey option plus field staff for an in-person survey option.

STANDARDIZING SURVEY ADMINISTRATION PRACTICES AND PROCEDURES

- Use trained data collection staff to read surveys to youth or assist youth (if needed).
- Avoid using peers or family members to assist youth with surveys.
- Staff should not exaggerate the inflection or tone of voice when reading survey questions.
- Staff should avoid looking at youth survey responses (and let youth know their responses are private).
- Staff should remain neutral or consistently give encouragement after youth mark their answers.

STRATEGIES FOR YOUTH WITH COGNITIVE DISABILITIES

Virtually and in person:

- Repeat the respondent's name often.
- Be attentive to behaviors that suggest the respondent needs a break—such as agitation or distraction.

In person:

- Keep the survey environment free of distractions.

Youth disability or special need	Accommodation
Learning disability	Read question(s) to youth individually or as a group (with safeguards to prevent youth from looking at each others' answers).
Autism	Change the lighting by brightening or dimming the light.
Sensory processing	Allow youth to wear headphones to screen out noise, play soft music, or listen to white noise.

Source: Kaplan (2021), NYTD (2010)

STRATEGIES FOR YOUTH WITH DEVELOPMENTAL DELAYS

Virtually and in person:

- Write/post the steps or directions
- Give more time.
- Take little breaks to relax or get up and move.

In person:

- Let the youth use red pens or writing instruments they choose.
- Let youth choose where they want to sit (e.g., floor, desk, couch).
- Give youth something squishy to play with during the survey (e.g., koosh ball).
- Hum to youth when they are stressed and let them hum as needed.

OTHER IDEAS

Virtually and in person:

- Provide genuine and gentle encouragement.
- Whisper instead of using a firm voice.
- Use humor.
- Audio record survey questions on an mp3 file or CD.
- Use visuals and colorful materials that grab youth's attention.
- Schedule surveys at a time when respondents are most alert and not, for example, at the end of a long school day.

OTHER IDEAS (CONTINUED)

In person:

- Offer tablet instead of paper and pencil.
- Ask youth to help pass out or take up materials
- Seat youth away from distractions, like windows or doors.
- Have youth sit near you, in a quiet area of the classroom, or provide an alternative seating option (such as a K'Motion Stool or pedaling device) that will help them focus.

K'MOTION STOOLS AND PEDALING DEVICE



GROUP ACTIVITY



OBTAINING PARENT CONSENT AND YOUTH ASSENT AND ENSURING PRIVACY

OBTAINING PARENT CONSENT

- Opportunity to learn about youth
- Not necessary to learn about the youth's disability or diagnosis

GUIDELINES FOR PARENT CONSENT FORMS



Provide parents with information about planned data collection procedures.



Mention possible accommodations.



Learn about youth needs for changes.



PROVIDE PARENTS WITH INFORMATION ABOUT PLANNED DATA COLLECTION PROCEDURES

- Day(s) of the week
- Time of day
- Staff training and experience
- Data collection mode and procedures
- How staff motivate and encourage youth
- Goals and expectations for data collection



MENTION THE POSSIBILITY OF PROVIDING ACCOMMODATIONS

- Encourages parent/guardian consent
- Facilitates thinking about what would be beneficial
- Empowers parents/guardians to ask for what their youth need



LEARN ABOUT YOUTH

- Can you suggest any supports you use at home, or that are used at school, that would be good for us to use when we conduct entry and exit surveys (e.g., visuals, schedules, etc.)?
- Is there information you would like our staff to know before your youth participates in the entry survey?
- Do you have any concerns about your youth participating in the surveys?
- Are there modifications or accommodations you can suggest that may encourage your youth's participation in the surveys?

OBTAINING YOUTH ASSENT

- Describe the data collection procedures you will use.
- Share the program goals and expectations for data collection—and why it is important that all youth be represented in the survey data.
- Give youth the opportunity to ask questions and express concerns.

ROLE PLAY



ENSURING PRIVACY

- Conversations about youth needs should be conducted in private.
- Information parents/guardians, youth, and others share about a particular youth should be kept confidential.
- Documentation about special needs or accommodations should be stored in locked filing cabinets, separate from survey data.
- Only staff who need to know this information should have access to it.

Q&A



TAKE-HOME POINTS

- Engage stakeholders to identify inclusive data collection practices to accurately represent all the youth you serve.
- Simple, practical accommodations can make a big difference.
- Identify specific strategies through communication with parents/guardians and youth.



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