Harnessing Person-Centered Planning Tools to Boost Individuals' Active Involvement in Designing and Participating in Their Own Care and Programming

By: Jenna Gilder Ph.D. BCBA LABA and Lauren Meyers Ph.D.

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Introductions

Lauren Meyers Ph.D.

Name: Lauren Meyers

Where you are from: I grew up in Mississippi, but currently live in Massachusetts.

Position/Organization: Clinical Director of CCSE Adult Services Division for May Institute.

Individuals you serve: I work with adults 22-end of life.

Why are you giving this presentation? Person centered planning and promoting dignity and respect for the individuals I serve is my mission!

Favorite leisure activity: Spending time with my dog Poppy!

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Introductions

Jenna Gilder Ph.D. BCBA LABA

Name: Jenna Gilder

Where you are from: I grew up in California, but I currently live in Massachusetts.

Position/Organization: Director of Clinical Services and Training at May Institute

Individuals you serve: I currently work with adults, but throughout my career I have worked with individuals aged 3 years old to end of life.

Why are you giving this presentation? I strongly believe that it is our ethical responsibility to the individuals we serve to include them as much as possible in all aspects and decisions impacting their lives.

Favorite leisure activity: Hiking or reading

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Conflicts of Interest

The presenters have no conflicts of interest to disclose

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Accuracy and Utility of Content

- Accuracy: The material discussed in this presentation is based on information gained from peer-reviewed publications and citations for these references are included throughout. The information in this presentation is intended to be applied by practitioners in the school, residential, and adult service settings.
- Utility: The recommendations provided in this presentation have utility for psychologists working in schools, residential, community, and adult day habilitation settings with individuals ranging from school-aged through adulthood.

BACB Ethics Code

Responsibility in Practice

- “2.01 Providing Effective Treatment Behavior analysts prioritize clients’ rights and needs in service delivery. They provide services that are conceptually consistent with behavioral principles, based on scientific evidence, and designed to maximize desired outcomes for and protect all clients, stakeholders, supervisees, trainees, and research participants from harm. Behavior analysts implement nonbehavioral services with clients only if they have the required education, formal training, and professional credentials to deliver such services.”

Responsibility to Clients

- “3.01 Responsibility to Clients (see 1.03, 2.01) Behavior analysts act in the best interest of clients, taking appropriate steps to support clients’ rights, maximize benefits, and do no harm. They are also knowledgeable about and comply with applicable laws and regulations related to mandated reporting requirements.”

(Behavior Analyst Certification Board, 2020)

APA Ethics Code

General Principles

- Principle A: Beneficence and Nonmaleficence
  - “Psychologists strive to benefit those with whom they work and take care to do no harm.”

- Principle E: Respect for Peoples Rights and Dignity
  - “Psychologists respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination.”

(American Psychological Association, 2017)

Outline

INTRO TO PERSON CENTERED CARE

INCLUSION IN HEALTHCARE

MEANINGFUL GOALS FOR SCHOOL AND DAYHAB

MEANINGFUL GOALS FOR THE RESIDENCE AND COMMUNITY

INCLUSION IN TRANSITION PLANNING

Outline

INTRO TO PERSON CENTERED CARE

Person Centered Values

"Science tells us how we can change things, but values tell us **what** is worth changing"

-Carr, 1996.

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Self Determination

- Self Determination: The attitudes and abilities involved in having control over one's own life
  - This involves being able to make choices and play a role in decision-making processes.

- Self determination is a basic human right and can contribute to quality of life (Kim, 2019).
  - Research has shown that individuals with ASD have less self determination than peers (Moran et al., 2020).
    - Therefore, it is up to US to support and encourage them to engage in self determination.

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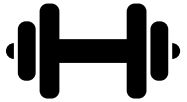
Person-Centered Planning

- Involves supporting individuals to take an active role in the decision-making process for goal development and life planning.
- Focus is on EMPOWERING the individual
- This planning then drives service development → Needs-Driven Planning

O'Brian & O'Brian, 2000; Santana et






When and in what contexts should you take a person-centered approach to involving the individuals in their care and life decisions?

All settings and as often as feasible







Focus Areas Today

INCLUSION IN HEALTHCARE

MEANINGFUL GOALS FOR SCHOOL AND DAYHAB

MEANINGFUL GOALS FOR THE RESIDENCE AND COMMUNITY

INCLUSION IN TRANSITION PLANNING

Outline

INCLUSION IN HEALTHCARE

Inclusion in health care

When improving health, buy-in is extremely important.

Having the buy-in of the individual can help to encourage lifestyle changes that can have lifelong health impacts (Bazzano et al., 2009).

Bridging Gaps and Barriers: Some healthcare providers may lack understanding, knowledge, and awareness about to how to support people with autism and intellectual disabilities, including how to make appropriate reasonable adjustments (Doherty et al., 2020).

Empowerment: Individuals' involvement in the decision-making process is an essential part of their health care. They feel empowered when they are involved in the decision-making process and gain a better understanding of their treatment and diagnosis (Doherty et al., 2020).

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Person-Centered Healthy Lifestyle Program (Bazzano et al., 2009)

This study looked at a community based healthy lifestyle program that included individuals with developmental disabilities in all stages of the development process.

It involved a twice-weekly exercise and education program that lasted 7 months.

44 adults with developmental disabilities completed the program

Results: 2/3 of participants maintained or lost weight, average BMI decreased and participants reported having healthier lifestyles

Strategies to prepare individuals prior to doctors' appointments:

Doctor's name: _____(filled in by staff)

Reason for appointment: _____(filled in by staff)

What do you want to tell your doctor today?

How are you feeling today:

Is there anything you want to tell the doctor:

Doctor's name: _____(filled in by staff)

Reason for appointment: _____(filled in by staff)

What do you want to tell your doctor today?

How are you feeling today (circle your choice):

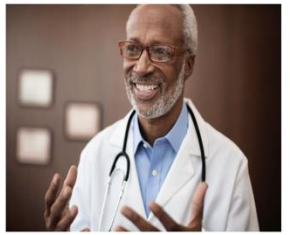
Good Okay Bad

Is there anything you want to tell the doctor:

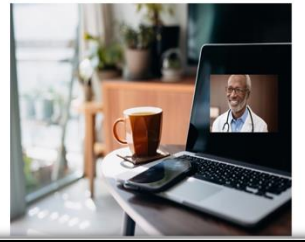
- _____
- _____
- _____

Seeing your doctor for your video visit:

Today you are going to see Dr. Mulligan about the medications you take in the morning with apple sauce



You will see him on the computer screen



Weight loss: 36-year-old Male

- Goal: individual wanted to lose 100 Pounds for his knees to feel better
- Developed a plan with staff to lose the weight and made a doctor's appointment to discuss healthy options to lose weight
- Took weekly progress photos

Diabetic: 46-year-old Male

- Goal: learn how to independently check blood sugar
- Discussed with doctor different devices and what types of sugar free treats he could still enjoy
- Shops with staff once a week to pick out sugar free candy
- Monitors blood sugar independently and asks staff for support as needed

Video model:

Outline

MEANINGFUL GOALS FOR
SCHOOL AND DAYHAB

Developing meaningful goals in school and dayhab

Why is this important?

- It is important to make sure that individuals have the critical life skills needed to increase their independence and overall quality of life (Bahry et al., 2023).
- It is also important, especially in the school setting when more resources are available, that we prepare students with the skills needed to be successful in adulthood (Bahry et al., 2023).
- Identifying goals that are important to the individual fosters belonging and allows the individual to identify with chosen community groups (Raines et al., 2023).
- Developing goals that are meaningful to the individual increases the desire to engage in the activity (Hassouneh, 2011).

Developing meaningful goals in school and dayhab

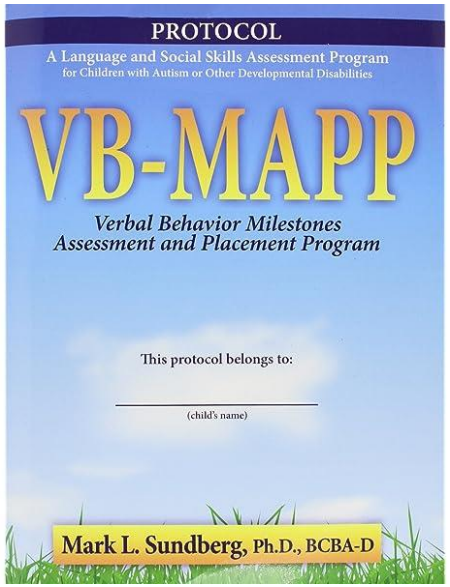
What is meaningful engagement:

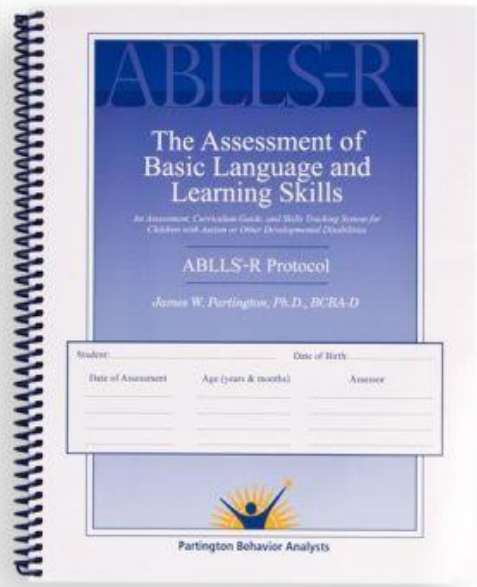
- It involves goals that are individualized to meet the individuals' needs.
- The goals should focus on achieving what is important to the individual.
- The goals should also be geared towards increasing independence in both the individuals' current and future leaning/living/community/and working environments.

(Ayres et al., 2011)

Developing meaningful goals in school and dayhab

Developmental assessments: Focus on catching individuals up to developmental milestones

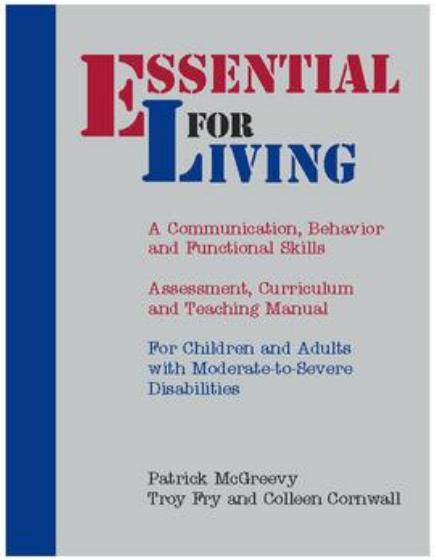


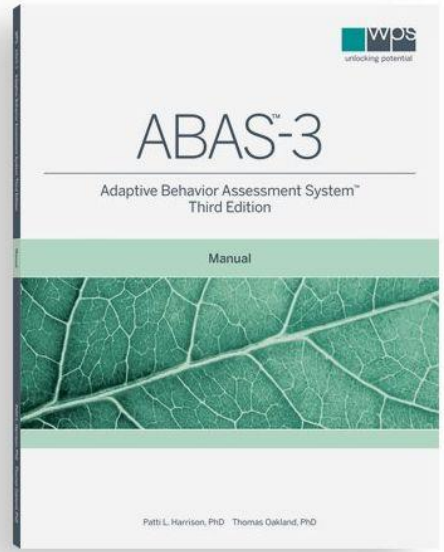


Bahry et al., 2023

Developing meaningful goals in school and dayhab

Adaptive Assessments: Look at critical life skills that will help increase independence in activities of everyday life





Adaptive skills tend to be the area to focus on to best prepare individuals for adulthood.

Bahry et al., 2023

When developing goals, focus on the WHY

Example: John will complete a lunch routine when at the school → **IN ORDER TO** increase his independence during mealtimes

Example: Emily will independently carry her communication device with her throughout the day → **IN ORDER TO** increase her communication of wants and needs

Gerhardt & Bahry, 2024

How to adapt goals: Focus on meaningful goals

Example school goal for someone who loves to cook:

Meal Prep Goal: John will increase his cooking skills by making 3 snacks independently across two different settings on three consecutive occasions.

*In order to: increase independence in the kitchen

Example school goal for someone who wants more independence in the community:

Purchasing Goal: Carol will independently make purchases at 3 different types of stores across 90% of opportunities.

*In order to: increase independence in the community

Example school goal for someone who has difficulty with waiting:

Waiting goal: Ronny will independently wait for 15 minutes for a preferred item or activity with two different staff present and across two different settings on 3 consecutive occasions.

*In order to: tolerate natural unavoidable delays

How to adapt goals: Focus on meaningful goals

Example day program goal for someone who enjoys working out

Wellness: At the Day Program, John will go to the gym with staff 3 times a week for 10 out of 12 months.

*In order to increase health and wellness

Example day program goal for someone who wants to become independent taking his medication

Independent Living: Jason will independently set his alarm to go take his medication from the nurse on 60% of days per month, for 10 out of 12 months.

*In order to increase independence

Example day program goal for someone who enjoys the community

Community: During community-based routines, Sam will increase her exposure to a variety of locations by attempting (being physically present with the absence of interfering behavior) and remaining in at least 2 new locations (e.g., movie theater, nature trail/parks, library, hardware stores, local museums, medical facilities) per month during the next DHSP year .

*In order to increase community engagement

Developing meaningful goals in school and dayhab

Check in on how individuals feel about goals and overall services with person-centered surveys and interviews

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Student Satisfaction Survey

Student Name: _____ Date: _____

School:_____ Staff assisting with survey: _____

Student assent to participate in survey (circle one): Yes / No

Please check all that apply - communication style of student/level of assistance needed:

___Independent ___ASL/gestural responses; staff asking questions

___Verbal responses; staff asking questions ___Communication tool for questions & answer

Today we are going to answer some questions about you and your school. There's no right or wrong answers. If there are questions that you don't understand, please ask.

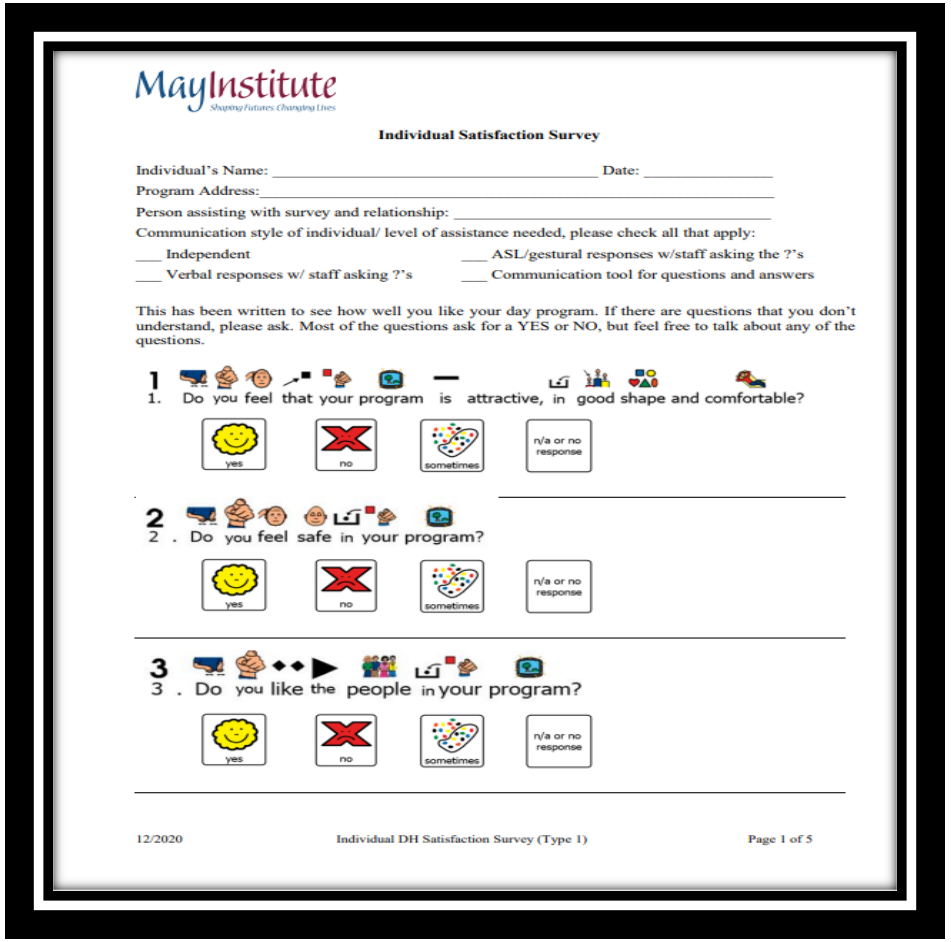
1. I like my classroom. No Response or N/A
2. I like activities in my classroom. No Response or N/A
3. I like my teachers. No Response or N/A
4. My teachers listen to me. No Response or N/A
5. I learned _____ at school.

Comments by Student:

_____

_____

_____



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Individual Satisfaction Survey

Individual's Name: _____ Date: _____

Program Address: _____

Person assisting with survey and relationship: _____

Communication style of individual/ level of assistance needed, please check all that apply:

___ Independent ___ ASL/gestural responses w/staff asking the ?'s

___ Verbal responses w/ staff asking ?'s ___ Communication tool for questions and answers

This has been written to see how well you like your day program. If there are questions that you don't understand, please ask. Most of the questions ask for a YES or NO, but feel free to talk about any of the questions.

1. Do you feel that your program is attractive, in good shape and comfortable?

yes no sometimes n/a or no response

2. Do you feel safe in your program?

yes no sometimes n/a or no response

3. Do you like the people in your program?

yes no sometimes n/a or no response

12/2020 Individual DH Satisfaction Survey (Type 1) Page 1 of 5

Developing meaningful goals in school and dayhab

Video model school:

Developing meaningful goals in school and dayhab

Video model dayhab:

Outline

MEANINGFUL GOALS FOR
THE RESIDENCE AND
COMMUNITY

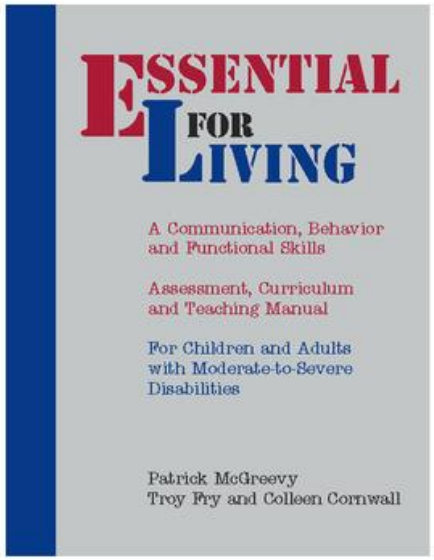
Developing meaningful goals in residential settings

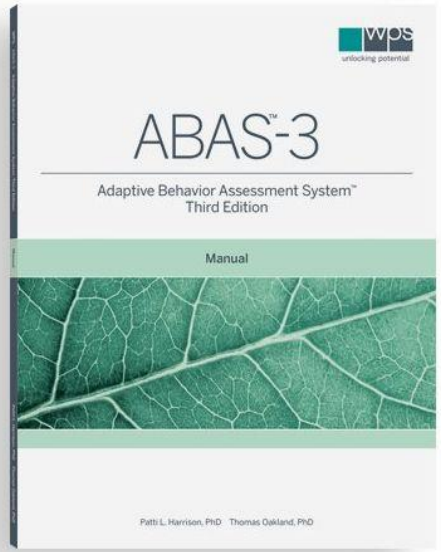
It is also important that we create meaningful goals in the residence.

- Individuals spend a large portion of their time in this environment, and it is a prime setting to work on independent living skills and community access skills.

Developing meaningful goals in residential settings

Adaptive Assessments: Look at critical life skills that will help increase independence in activities of everyday life





Bahry et al., 2023

Developing meaningful goals in residential settings

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Individual Meeting Minutes (1of 12)

Program: _____

Date: _____

Attendance:

_____

_____

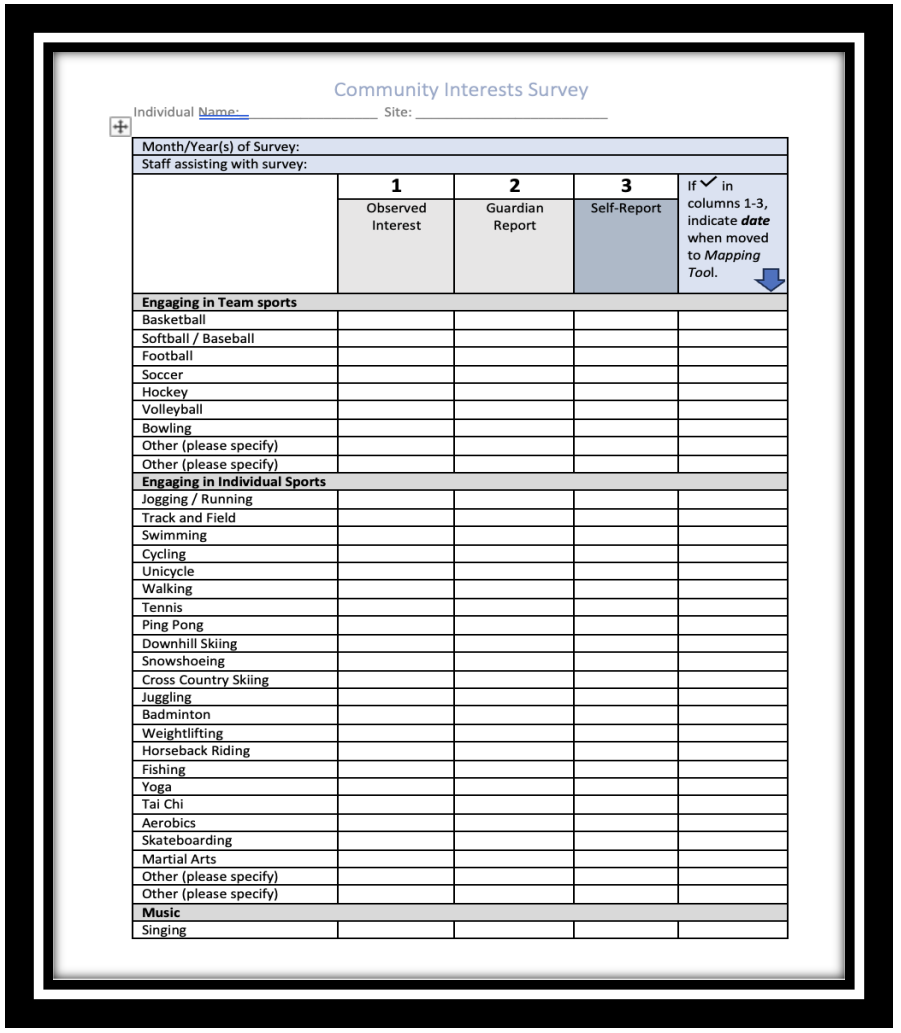
_____

Human Rights Topic #1: You have the right to live in an environment that is clean, in good repair, and as home-like as possible.

Human Rights Topic #2: You have the right to wear your own clothing. This includes having personal clothing that fits properly and is appropriate for the season.

Fire Safety/Disaster Topic: If smoke/fire is blocking the primary exit, you need to exit out of an alternate exit. Where is the primary exit? Where is the secondary exit?

What are you most excited to talk about?



Community Interests Survey

Individual Name: _____ Site: _____

Month/Year(s) of Survey:				
Staff assisting with survey:				
	1 Observed Interest	**2** Guardian Report	**3** Self-Report	If ✓ in columns 1-3, indicate ***date*** when moved to *Mapping Tool*.
Engaging in Team sports				
Basketball				
Softball / Baseball				
Football				
Soccer				
Hockey				
Volleyball				
Bowling				
Other (please specify)				
Other (please specify)				
Engaging in Individual Sports				
Jogging / Running				
Track and Field				
Swimming				
Cycling				
Unicycle				
Walking				
Tennis				
Ping Pong				
Downhill Skiing				
Snowshoeing				
Cross Country Skiing				
Juggling				
Badminton				
Weightlifting				
Horseback Riding				
Fishing				
Yoga				
Tai Chi				
Aerobics				
Skateboarding				
Martial Arts				
Other (please specify)				
Other (please specify)				
Music				
Singing				

How to adapt goals: Focus on meaningful goals

Example residential goal for someone who wants more independence in the community:

Community goal: Paul will help plan, using a written checklist, and engage in at least six community activities a month with 90% independence (measured using his score on the written checklist), for 10 out of the 12 months.

Example residential goal for someone who wants to be more independent with meal-time:

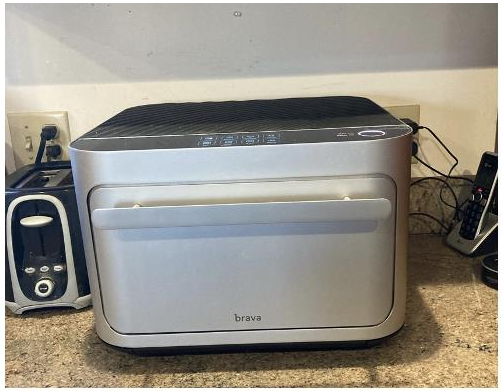
Independent living goal: Sophie will independently use two kitchen appliances (examples: microwave, blender, toaster, oven/stove) with 90% independence for 10 out of 12 months.

Example residential goal for someone who needs assistance with daily living skills:
ADL Goal: Henry will complete his dental routine (brushing and flossing) with 80% independence across opportunities for 10 out of 12 months.

Technology promoting goal independence in residence

How to Use the Brava Oven

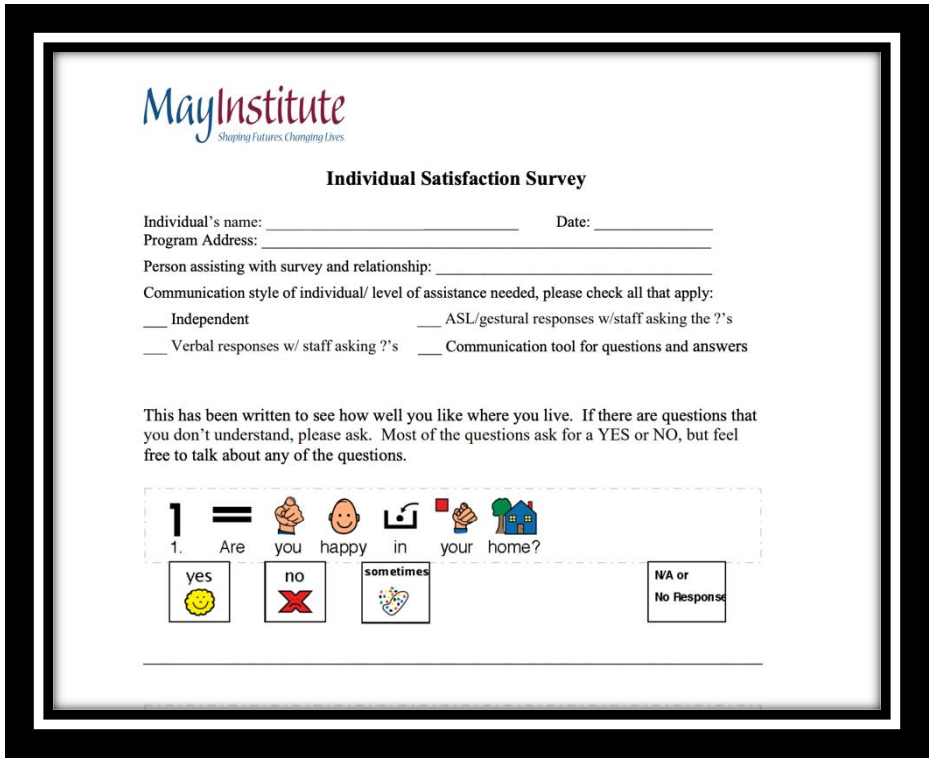
1. Go over to the oven



2. Press the on button

Developing meaningful goals in residence

Check in on how individuals feel about goals and overall services with person-centered surveys and interviews



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Individual Satisfaction Survey

Individual's name: _____ Date: _____
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Communication style of individual/ level of assistance needed, please check all that apply:

___ Independent ___ ASL/gestural responses w/staff asking the ?'s

___ Verbal responses w/ staff asking ?'s ___ Communication tool for questions and answers

This has been written to see how well you like where you live. If there are questions that you don't understand, please ask. Most of the questions ask for a YES or NO, but feel free to talk about any of the questions.

1. Are you happy in your home?

yes | no | sometimes | N/A or No Response

Developing meaningful goals in residential settings

Video model

Outline

INCLUSION IN
TRANSITION PLANNING

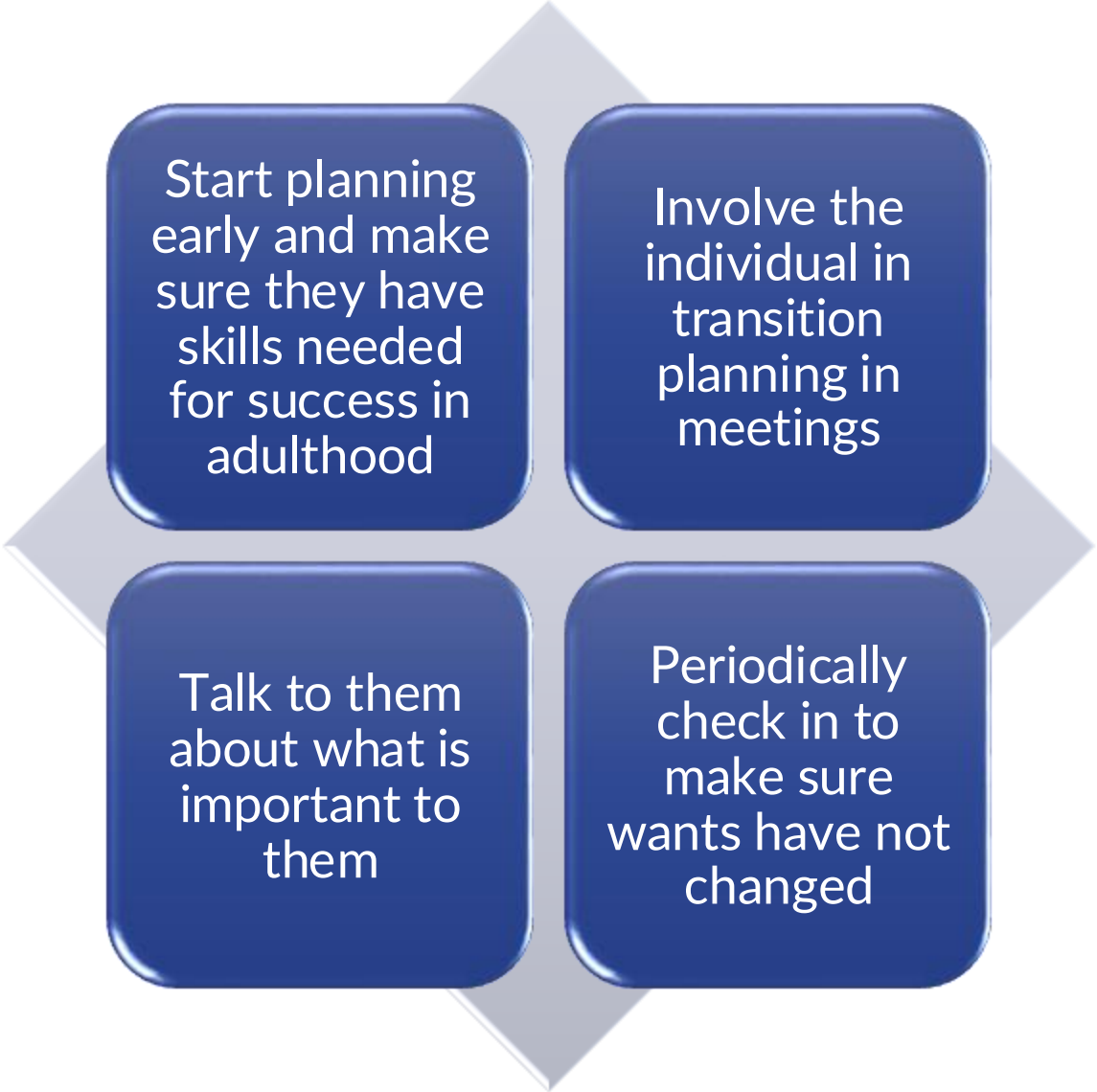
Person-Centered Transition Planning

Why is this important?

Person-Centered Planning:

- Including the individual into their transition planning prompts person-centered planning (Lindstrom, 2020)
- Strengthens expectations for and breaks stereotypes about students with disabilities (Lindstrom, 2020).
- Creates inclusion that can assist with the transition adjustment (Miller, 2020).

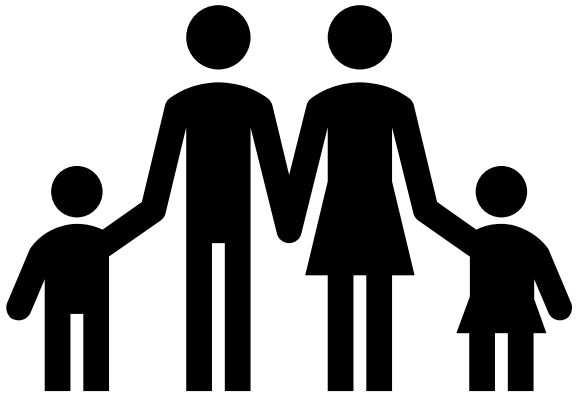
Person-centered transition planning



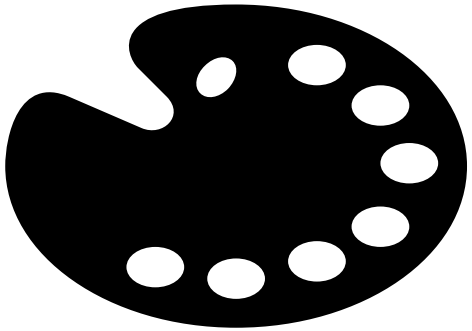
(Gerhardt & Lainer, 2010)

Person-centered transition planning

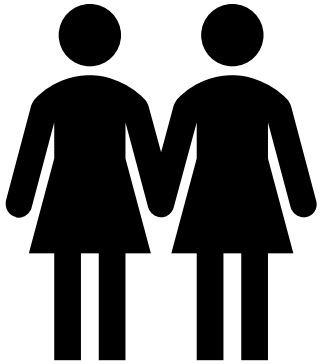
Case examples:



Placement close to family



Art programming



Peers of similar ages

Person-centered transition planning

Video model:

Bringing it all together

How can you bring what you learned today back to your program?

1. Always make sure that the voices of the individuals you serve are heard, you can use the handouts to help with this.
2. Find out what the individuals find meaningful in life and create programming around their values.
3. Plan for adulthood early.
4. Lastly, take an extra moment to step back and remind yourself that this is their life and that our role in it is to support them to live the life that they want.

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