

ACHIEVING HEALTHIER FUTURES ONE STEP AT A TIME

Communication Tips for
Interacting With People With
Intellectual and/or Developmental
Disabilities

The Arc 2019 Toolkit

ACHIEVE WITH US
ONE STEP AT A TIME



TABLE OF CONTENTS

The purpose of this toolkit is to familiarize the user with intellectual and developmental disabilities (I/DD) and communication techniques to assist in successfully facilitating a healthy living program for individuals with I/DD. These are suggested techniques particularly helpful for those who don't have any experience working with individuals who have I/DD.

What is I/DD and How Does it Affect Health?.....	3
The Trouble with Labels	5
Communication Strategies	6
Challenging Behaviors.....	9
Preparing for Success	10
Additional Resources.....	12

WHAT IS I/DD AND HOW DOES IT AFFECT HEALTH?

Intellectual and developmental disabilities (I/DD) is an umbrella term for disabilities that become apparent during early childhood. Often individuals will have a dual diagnosis (both an intellectual and a developmental disability).

Intellectual disability (ID) is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in communication behavior.

Intellectual disability:

- Can be mild, moderate, or severe
- Presents symptoms before age 18
- Common ID diagnoses include: Down syndrome, Prader Willi Syndrome and Fetal alcohol spectrum disorders
- Each diagnosis has unique characteristics, causes, and associated health conditions.

Developmental disabilities are a group of conditions characterized by an impairment in the areas of physical, learning, language, or behavior.

Developmental disability:

- Encompasses intellectual disabilities, but can also include physical disabilities as well
- Typically presents during the developmental period
- May impact day-to-day functioning
- Lasts throughout a person's lifetime
- Common diagnoses include: Cerebral Palsy, Fragile X Syndrome, and Muscular Dystrophy



WHAT IS I/DD AND HOW DOES IT AFFECT HEALTH?

Autism Spectrum Disorder (ASD) is a very common diagnosis. ASD is not technically an intellectual disability, although an individual with ASD can have an additional diagnosis of ID as well.

- Currently 1 in 59 individuals in the USA are diagnosed with ASD.
- ASD is a spectrum, which means that the level of support needed for these individuals ranges from mild to intensive.
- There are no common physical characteristics for ASD. You cannot visually see autism.
- Everyone with an ASD diagnosis is impacted in the areas of social, communication and behavior with symptoms presenting themselves in early childhood.
- To learn more about ASD, visit cdc.gov/ncbddd/autism/signs.html

Statistics show that obesity rates are **58% higher** for adults with disabilities than for adults without a disability. Adults with disabilities find it more difficult to eat healthy, control their weight and be physically active due to lack of healthy food choices and nutrition education, medication side effects, physical limitations, and a lack of accessible environments that enable exercise.

Statistics also show that regular physical activity provides important health benefits for people with disabilities, including improved cardiovascular and muscle fitness, mental health, balance, and the ability to better perform daily life tasks.



THE TROUBLE WITH LABELS

Many times, when we hear a label attached to a person, we automatically make assumptions about what that individual can and cannot do. But individuals with I/DD are not defined by their diagnostic label. Just like you or I, they are an individual who has their own likes and dislikes, their own goals and aspirations. When communicating with and about individuals with disabilities, we should use person-first language.

What is person-first language?

Person-first language focuses on the person rather than the disability and utilizes word choices which refer to the individual first and then the disability.

For example, if I have a dairy allergy, you would not call me a “dairy allergic person,” you would call me a “person with a dairy allergy.” Similarly, someone with I/DD is not a “disabled person,” but rather, “a person with a disability.”

However, some people prefer identity-first language (Ex: autistic person). You should always respect how a person wants to refer to themselves if they communicate a preference.

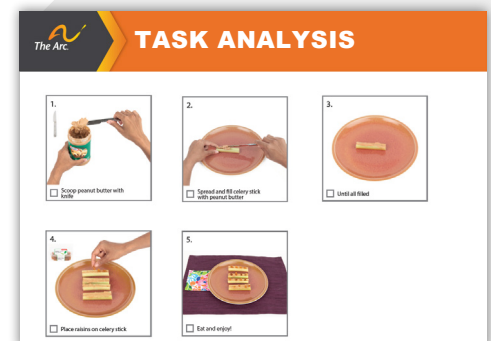


COMMUNICATION STRATEGIES

Our word choice, tone, volume, and body language all affect how others receive the messages that we are trying to get across.

Here are some tips for encouraging participants to understand and respond to instructions:

- Phrase instructions in the form of a *command* instead of a *question*.
Ex: "It's time to walk to the gym" versus "Can you walk to the gym?"
- When giving instruction, use concrete, specific language.
Ex: Instead of saying "settle down," we might say: "inside voice", "walking feet", "hands to yourself"
- Use "first/then" statements to give ordered instruction
Ex: "First, we'll walk for 15 minutes on the treadmill. Then, we'll dance to your favorite song!"
[Find more information on "first/then" statements.](#)
- Place instructions **one step at a time**
"Make a healthy salad for lunch" may seem like a simple demand, but to ensure that we are being understood, let's detail out the steps required to complete the task. This is called a [task analysis](#).
 1. Get lettuce out of the fridge
 2. Wash lettuce
 3. Chop lettuce on a board
 4. Put lettuce in a bowl
 5. Add grilled chicken
 6. Add low-fat dressing
 7. Add dried fruit
 8. Enjoy!



Access healthy recipe task analyses that you can try today at accessiblechef.com!



WALK THE WALK

Modeling can be a powerful tool! Modeling is demonstrating the action or behavior for the participant. This can be done in person or through the use of video for more complex tasks, such as making a recipe or completing an exercise routine.

Video Example: [Modeling the Creation of a Healthy Snack](#)

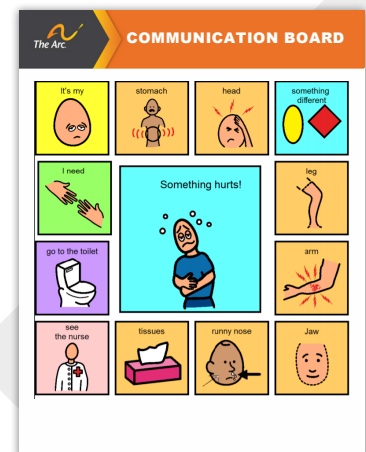


NON-VERBAL PARTICIPANTS

Some program participants may be non-verbal. Expressing wants, needs, and likes is important for everyone — and just because someone cannot *verbally* tell you what they want or need doesn't mean that they are not able to *communicate*. Below are some tips to try when communicating with someone who is non-verbal.

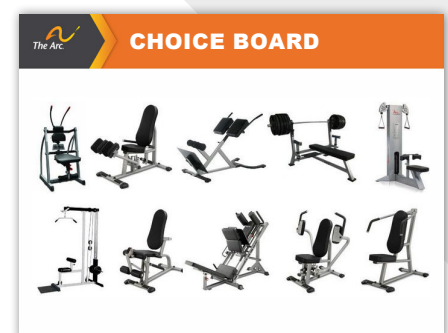
Try a communication board

- You can find one online or make your own by pasting pictures relevant to the task onto a white piece of paper. Be sure to leave enough space in between pictures so that the participant can clearly identify what they want.
- Think about what you want the participant to be able to tell you. What are they going to use most often? What is going to make the biggest impact for them?
- The Arc has an [example communication board](#) that participants can use to tell you when something is hurting them.



Choice boards

- By offering program participants choices, you increase opportunities for engagement. Choice boards allow the participant to see exactly what their options are at a moment in time. Ensure the participant can understand and identify each choice. The participant can then make an autonomous decision as to what they would like to do.
Ex: If it's time to exercise, you might use a choice board like [this one](#) to let a participant choose which exercise machine they'd like to use.
- Learn more about creating and utilizing choice boards at autismcircuit.net/tool/choice-board.



COMMUNICATION STRATEGIES

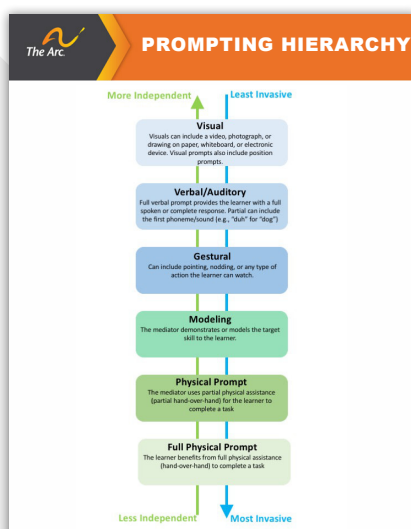
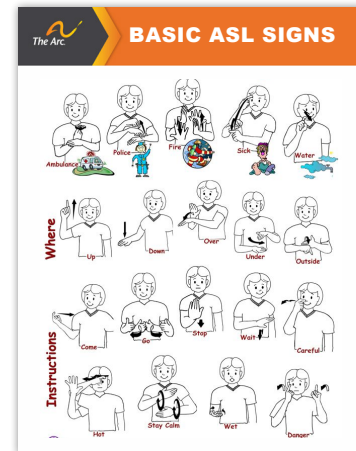
American Sign Language (ASL)

- If you have a participant who uses ASL, you'll want to reference some common signs to assist in your communications.
- [Here](#) is a quick reference guide to get you started.
- You can find short video tutorials [here](#) and [here](#).

PROMPTING HIERARCHY

Sometimes you might be tempted to do a task for a participant who appears to be struggling. No matter how tempting that may be, resist! You want your participants to be as independent as possible. Prompting hierarchies can help us provide *the right amount of help* without completely taking over. Always start with the lowest prompt possible and make sure you are fading these out over time so that participants do not become dependent on your prompting. The idea is to move from *least intrusive* prompts to *most intrusive* prompts with wait time in between each step.

The Arc has a [free printable resource](#) on the Prompting Hierarchy.



CHALLENGING BEHAVIORS

When challenging behaviors occur, we must ask *why* the participant is behaving this way. It's not personal, but a form of communication! There are four main reasons why someone may be engaging in challenging behaviors. To help us remember all four we use the acronym **S.E.A.T.**

- **SENSORY** behaviors feel good, they can occur anytime, including when the individual is alone. Keep in mind this is the least common reason why someone is misbehaving.
- **ESCAPE** behaviors remove a participant from an undesired activity. They give the individual a temporary or permanent break from the task/situation. This is a very common "why".
- **ATTENTION** behaviors provide access to attention from others. This can be verbal, non-verbal, good, or bad. This is also a very common "why".
- **TANGIBLE** behaviors provide access to preferred activities or items. They occur when an individual wants access to an item or can be in response to being denied access to an item. This too is a very common "why".

An important note... sometimes, we can have more than one "why". The goal with identifying our "why" is to **REPLACE** the challenging behavior with an adaptive behavior that gets the individual what they want.

Q: What do I do if a participant is having a challenging behavior?

A: Respect personal space
Speak calmly, firmly, and respectfully
Avoid power struggles, arguing, or becoming defensive
Listen actively
Be brief and minimize talk
Maintain neutral body language
State directions positively (what you want them to do vs. not do)
Allow wait time
Acknowledge cooperation



PREPARING FOR SUCCESS

Antecedent Based Interventions are ideas that you implement to *prevent* challenging behaviors from occurring in the first place. Some ideas might include:

Rearranging the environment

- Setting boundaries by using room dividers, furniture or tape
- Removing distractions such as items, sounds, or people

Using schedules

- Low preference activities first, then high preference activities; *work then play*
- Offer more breaks from demands to increase engagement – then gradually decrease break time
- Provide advanced notice for any changes in routine.
Ex: “Tomorrow’s class will be at the swimming pool instead of in the gymnasium. Let’s talk about how we will prepare for tomorrow’s class...”

Offering choices

- Allow participants to choose things like where to work on tasks (table, chair, carpet) or how to transition from one location to the next (walk, run, hop).

Alternating instructional approaches

- Change *where* class is held
Take it outside! Visit a park, the zoo, or a grocery store.
- Change *how* class is held
Engage in active storytelling when reading a lesson-plan; vary your tone, volume, and facial expressions.

KNOW WHEN TO ASK FOR HELP!

If you are working with a participant who exhibits aggressive behavior toward others or themselves, or who engages in property destruction, you should seek help in managing those behaviors. Perhaps the participant’s parent/guardian can attend class with them and help reinforce your positive communications. Perhaps the participant is working with a Board-Certified Behavior Analyst (BCBA) who can attend class with them and actively redirect undesired behaviors.

There is **nothing wrong** with asking for help. Achieving successful communication and program engagement is a process! With a positive attitude, you and your participants will achieve, *one step at a time*.

ACKNOWLEDGEMENTS



The Arc would like to thank The Arc of San Antonio, the South Texas Behavioral Institute, and The YMCA of Greater San Antonio for their role in developing this toolkit.



FREE RESOURCES

Accessible Chef - <https://accessiblechef.com/>

ASL Basic Sign Language Words - <https://www.startasl.com/basic-words-in-sign-language/>

ASL Video Tutorials - <https://www.lifeprint.com/asl101/pages-layout/concepts.htm>

Autism Internet Modules - <https://autisminternetmodules.org/>

Boardmaker (free trial) - <https://goboardmaker.com/pages/boardmaker-online>

CDC Autism Resources - <https://www.cdc.gov/ncbddd/autism/links.html>

CDC Signs and Symptoms of Autism Spectrum Disorders - <https://www.cdc.gov/ncbddd/autism/signs.html>

CDC Disability and Obesity - <https://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html>

CDC Communicating With and About People with Disabilities PDF - https://www.cdc.gov/ncbddd/disabilityandhealth/pdf/disabilityposter_photos.pdf

Choice Boards - <http://www.autismcircuit.net/tool/choice-board>

NCHPAD - <https://www.nchpad.org>

The National Professional Development Center - <https://autismpdc.fpg.unc.edu/>

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