NASP
NATIONAL ASSOCIATION OF
School Psychologists

# Intellectual Disability: Helping Handout for Home

FRANK J. SANSOSTI & DARLENE UNGER

## INTRODUCTION

When a child is identified as having an intellectual disability (ID), it means the individual has significant limitations in intellectual functioning (also called cognitive ability or thinking and reasoning ability) and in adaptive behavior, or the skills needed to live independently (American Association of Intellectual and Developmental Disabilities [AAIDD], 2012). Children with ID require varying levels of support throughout their lives to participate successfully in school, home, work, and community activities. The family plays an important role in planning these supports and in using them at school, at home, and in the community.

Children with ID receive services at school as required under the Individuals with Disabilities Education Improvement Act (2004). A child's Individualized Education Program (IEP) guides the services provided and requires annual monitoring of progress. It is developed by a team that includes parents and, when appropriate, the child. The IEP should address the development of your child's academic, social and communication, vocational, and independent living skills. The team will consider and include in the IEP ways that your child can be served in the least restrictive environment (LRE). That is, your child should have opportunities to learn and receive support services in classrooms with typical peers.

The school may use positive behavioral interventions and supports (PBIS; Sugai et al., 2000), which may help in reducing challenging behaviors and increasing inclusion in regular classrooms. The school or your local office of services for individuals with developmental disabilities also may offer person-centered planning as a process for developing your child's IEP, future goals, and needed supports. Person-centered planning helps to identify your child's "hopes and dreams," or the long-term outcomes you want for your child's life, as well as the strengths and resources your child has at home, at school, and in the community. These strengths and resources are then used to develop supports that will help your child reach short- and long-range goals. One advantage of person-centered planning is that it addresses the life skills that are often overlooked during IEP planning and K–12 educational services, which tend to focus on academics.

Community supports may be available through the Home- and Community-Based Services (HCBS) Waivers, which is part of a state's Medicaid program. Waiver programs differ across states, but they represent a means for long-term care and support services for families, by providing certain medical and nonmedical services aimed at increasing the individual's independence and inclusion across the lifespan. Even if your family does not meet traditional income eligibility criteria for Medicaid, you may be able to access supports through HCBS Waivers given your child's support needs. These services, such as respite or day care, behavioral therapy, vocational therapy, and speech and language therapy, give families choice and control in the selection of supports so their child can remain at home and in inclusive settings. Unfortunately, public resources allocated to family support services, such as HCBS, have become increasingly limited (Braddock et al., 2015). Families should contact the local office of their state's developmental disabilities agency (http://www.nasddds.org/state-agencies/) or the local office of the agency that administers Medicaid (https://www.medicaid.gov/) to explore available waiver options. The harsh reality is that caregivers of individuals with ID often encounter waiting lists for non-IDEA-funded services, limited availability of service providers, and inconsistent quality of services.

 

## WHAT TO CONSIDER WHEN PLANNING INTERVENTIONS AND SUPPORTS

When planning for supports in the home, it is important for families to consider using strategies that have proved effective in addressing children's behavioral challenges or learning needs during the school day. Using the same strategies across school, home, and community settings helps the child learn and practice skills and expected behaviors over time and in different situations.

Given the varying abilities and challenges of individuals with ID, it is important to adapt strategies aimed at increasing the child's independence and self-determination. Self-determination means that individuals have opportunities to exert control in their own lives, make choices and decisions, and advocate on their own behalf (Wehmeyer, Kelchner, & Richards, 1996). Children need to be provided with opportunities, as well as the supports necessary, to participate in activities (e.g., chores, social/recreation) similar to peers, to make informed decisions, and to speak or communicate their desires. Supports may include role-playing situations, providing guided practice to the child, and teaching the child to use visual supports (e.g., graphic organizers, checklists, video models).

Problem-solving skills also are an important part of self-determination. Because children with ID may have difficulty identifying possible solutions or choosing a course of action for a challenging situation, directly teaching steps in problem-solving is necessary. Problem-solving instruction involves teaching individuals with ID to (a) communicate the problem, (b) make suggestions for how to fix the problem, and (c) evaluate if the strategy is working. These behaviors make it more likely your child will be successfully included in general education settings. They also increase the chances to participate in positive postsecondary experiences and eliminate the need for sheltered workshops (Simonsen & Neubert, 2013).

It may be challenging for parents to avoid intervening when a family member with ID is having difficulty arguing with a sibling, or communicating with a new friend or a cashier in a store or restaurant. However, when individuals with ID have the opportunity to solve problems and increase self-determination, they are more likely to have positive postsecondary outcomes, including employment, independent living, and community inclusion (Wehmeyer & Palmer, 2003). Regardless of their aptitude, findings consistently demonstrate that cognitive ability (or IQ) is not predictive of self-determination status. Instead, factors such as participation in inclusive environments, communication skills, and opportunities for making choices are predictive of self-determination in individuals with ID (Shogren et al., 2007). Thus, providing experiences that allow youth to express their thoughts or beliefs, problem-solve, participate in family decision-making, and set and track progress toward goals all help to build critical self-determination skills.

The relationships between the individual with ID and family members, peers, and other potential caregivers are important to consider in planning supports. Having a child with ID may increase stress in relationships, but it may also strengthen those relationships. Caring for an individual with ID places increased demands on family members, so it is important to understand how caregivers respond to stress and how these responses affect the individual with ID. For example, when a child's behavior escalates, caregivers may give in to the child, which increases the likelihood of misbehavior in the future. Or they may use punishment or aversive procedures. Aversive techniques use painful or unpleasant experiences to modify an inappropriate behavior. Although effective in the short term, the use of aversive techniques should be avoided. Positive behavioral interventions and supports are the preferred approach for addressing challenging behaviors. These strategies require consistent procedures and responses to help address challenging behavior, given the various demands on families and caregivers.

## RECOMMENDATIONS

Evidence-based strategies for improving behavior and adaptive skills in the home are categorized as (a) prevention approaches and (b) intervention strategies. Both aim to reduce challenging behaviors and increase the individual's self-determination behavior. Because the needs and abilities of children with ID can vary significantly, some of the approaches may be more applicable than others for your child.

**Prevention Approaches**

1. ***Conduct a home environmental assessment and develop an action plan.*** This process (see Braddock & Rowell, 2011) uses the following steps

to identify the greatest challenges and stressors caregivers experience in the home environment:

- Hold a discussion involving all people living in the home, including the child with ID, to assess the greatest challenges and stressors experienced in the home environment. For example, consider how the physical environment and routines in the home may contribute to challenging behaviors. Is one family member often awake and active while others are asleep? Do caregivers need to make special arrangements to leave the home (that is, the child with ID may be injured if unsupervised)? Do stairs present an obstacle for independence?
- Identify environmental modifications, including routines in the home, as potential strategies to address identified challenges. For example, building a fence around the yard may allow the child to play outside with limited supervision. Establishing routines for bedtime and wake-up times, personal hygiene, and self-care skills may encourage the child's independence and self-reliance, lessening the demands for assistance from caregivers.
- Develop an action plan that is appropriate and manageable to address the unique situation and circumstances. In some instances, structural modifications to the home, although potentially costly, might be needed. To explore potential resources and solutions, contact the local office of developmental disabilities and speak with a service coordinator or case manager about your family's needs.

2. ***Identify support systems in the home and community.*** The following are ways to enlist family, friends, peers, and agency representatives in providing supports:
   - Within the home environment, identify systems of supports that can be provided by family members or friends and peers. Organizing this help will involve developing a schedule so that several helpers can provide support across activities associated with daily living and community participation. By identifying several individuals who can provide support for a specific task (e.g., participating in the children's reading group at the public library or weekly or monthly social and recreational activities), you can ensure continuity of assistance and familiarity for your child.
   - Communicate with school representatives about the availability of peer mentors. Peer mentoring and buddies programs are gaining in popularity across K–12 schools. In these programs, peers provide support for students with ID in a variety of inclusive environments (see, e.g., http://www.kypeertutoring.org/).
   - Communicate with representatives from educational or disability agencies to identify potential out-of-school mentors for your child. For example, colleges and universities sometimes have programs in which students mentor individuals with disabilities or coordinate events for individuals with ID to attend, such as university student chapters of the Council for Exceptional Children, Best Buddies International, Easter Seals, and Special Olympics.
   - Use Web-based resources of agencies supporting individuals with ID to identify information programs to help siblings and peers explore and exchange ideas for connecting your child with others in mutually beneficial way (e.g., http://mylifewithoutlimits.org/).
   - Communicate with your child's school psychologist or special educator to identify formal agency-provided support options. These options may include service coordination or case management through the local Office for Developmental Disabilities, day or respite care providers, and other related supports. Explore public resources that may be available to offset costs associated with services, such as Medicaid HCBS Waivers, ABLE Accounts, or Supplemental Security Income.
   - Connect with other parents of children with ID to share resources and strategies and gain emotional support. You can identify local resources by contacting a representative from your state's chapter of The Arc, the state office for people with developmental disabilities, and other Web-based services (e.g., Parents Helping Parents).

3. ***Establish short- and long-term goals.*** Setting specific goals can help both you and your child stay on track for developing the child's independence. Be sure to include a plan for evaluating progress toward the goals, by considering the following steps:
   - With your child, identify and write down short- and long-term personal goals (i.e., less than

1 year and 3–5 years) aimed at increasing independence and self-determination. For example, goals might include learning money skills by shopping in the community, opening a bank account, and developing a budget.
    - Use a visual aid, such as a line chart, so your child can see the goal, the steps needed to accomplish the goal, and progress toward the goal. Note progress toward goals and coach your child to maintain his or her own progress. For example, use a personal calendar to record banking deposits and transactions.
    - Enlist caregivers in providing opportunities for the child to work toward the goal.
4. ***Establish schedules and consistency of routines.*** Create a chart of daily routines and practice reviewing it and updating it, such as follows:
    - Discuss with family members daily routines for school or work days and develop a coordinated schedule for use of bathrooms, mealtimes, and wake-up and sleep time.
    - Provide schedules using text, pictures, or video for the use of shared spaces (e.g., bedrooms, bathrooms) and items (e.g., computer, television, video gaming systems). Develop a system so that your child can self-monitor following the rules.
    - Support the child in reviewing and monitoring the daily schedule of before-school and after-school routines and chores. For instance, post a checklist of chores that includes when each should be completed. Have the child check off each chore as it is accomplished.

**Intervention Approaches**

5. ***Practice and implement coping and stress reduction strategies.*** The following methods can be used to help your child reduce stress and regulate emotions:
    - Practice mindfulness-based stress reduction strategies. These strategies include formal instruction in meditation, breathing, and relaxation techniques. Integrating mindfulness practices into everyday life increases coping ability and decreases reactivity to physical and emotional difficulties (Bazzano et al., 2013).
    - Develop specific strategies your child can follow for coping and reducing stress when prompted or necessary. For example, you might have a visual display of a five-step process for calming down. Your child can practice thinking "When I am frustrated, angry, or upset, I will choose to (1) Remind myself that it is never okay to hurt others. (2) Take three deep breaths or count slowly to 10. (3) Use my words to say how I feel and what I wish would happen. (4) Ask for help or ask to take a break. And (5) take the time I need to calm down." When your child is becoming upset, prompt use of the strategies by pointing at a visual representation and using a simple verbal instruction, such as "Time to breathe!" Reinforce your child's efforts to manage emotions.
    - Teach your child to recognize environmental factors that increase anxiety, such as bullying or trauma, transitions, new situations, stressful academic or work tasks, or illness. Provide examples and nonexamples. For example, use pictures to demonstrate and explain the difference between accidents (when a person didn't mean for something to happen) and something done on purpose (when a person meant for something to happen), such as a bump in the hallway versus being shoved. Pictures also could be used to teach about body language, facial expressions, and environmental clues.
    - Use prompting to teach your child to recognize when to use the coping strategy. Prompting means to provide verbal, gestural, or physical support to get your child to initiate the coping strategy. Over time, use fewer prompts and promote self-regulation, which means that your child independently identifies situations that cause anxiety and then implements specific coping strategies.
    - Teach the child to communicate feelings through the child's preferred communication systems, such as verbally, through gestures, or using an assistive device.
    - Establish private places in the home where your child can feel safe and in control.
6. ***Establish clear expectations and support positive behavior.*** Giving children clear expectations helps them be more aware of their environment and better control their responses, as suggested in the following strategies:
    - Provide opportunities for your child to contribute in discussions and decisions about behavioral expectations in the home and the community. For example, when going to a store or a community event, clearly

communicate about how long the outing will last, what the child can expect to happen, the purpose of the visit, and the behavior expected from the child. When appropriate, ask the child about preferred activities during these opportunities and allow the child to make decisions about purchases or meals.

- Limit the use of punishment, such as scolding the child or withholding favorite activities (e.g., not allowing television). Instead, try redirecting the child's focus toward another desirable or acceptable behavior. For instance, if your child is fighting with a sibling, you might call the child by name and offer to read a book or point to a favorite toy to redirect attention away from the argument. If the behavior is irritating or annoying, but not threatening or harmful, you may choose to ignore the behavior and look away.
- When your child shows the behaviors you want to see, use immediate praise, such as "Great job, Tim! I like how you went to clean your room quickly when I asked you."
- Offer tangible reinforcers, such as the child's favorite toy or a sticker when the child engages in the expected behavior.

7. ***Teach your child to perform daily activities.*** Use modeling and visual aids to teach skills needed to perform self-care (e.g., grooming, hygiene, and safety), domestic tasks or chores, and play or recreational activities in the following ways:
   - For skills that require multiple steps or behaviors, such as brushing teeth or getting dressed, break down these challenging tasks into specific, observable steps. Then demonstrate how to do each step. For instance, say "Pick up the toothpaste" as you demonstrate picking up the toothpaste. After you are done with the demonstration, ask your child to perform the same steps, providing prompts or support as needed.
   - Develop a checklist with pictures or photos of your child doing each step as a reminder of how to do the task.
   - Give your child opportunities to practice and use the skills at home and in other settings where the skill or behavior might be needed. For instance, have your child take dishes to the sink or dishwasher in your home or take the plates or trays to the appropriate place in a self-serve restaurant.
8. ***Be prepared and teach your child necessary safety skills.*** It is important for children with ID to be aware of potential dangers and to learn skills they can use to protect themselves, as in the following examples:
   - Eliminate or secure obvious hazards and safety risks in your home. Store medications and household cleaning products in locations that are secure and not easily accessible to your child.
   - Some children with ID may have difficulty with their surroundings (e.g., changes in temperature, lighting, noise). Provide supports like headphones or layers of clothing. Teach active strategies when environmental changes are needed. For example, teach your child how to recognize the need for adjustments in lighting or temperature and to ask someone.
   - Teach your child to recognize and react to emergency situations, such as calling an adult or dialing 9-1-1 (register with emergency call centers to share disability-related information; www.smart911.com). You can use role-playing, hypothetical scenarios, videos, and pictures to show ways of getting out of a burning building and calling for help. It is important to share examples of individuals responding appropriately and examples where individuals did not react correctly. Arrange opportunities to speak to emergency responders (e.g., firefighters and police officers) so your child will not be afraid in situations where such individuals are present. Practice for these situations regularly and discuss examples in movies, television, or the newspaper. Ask how your child might respond.
   - Do not overlook the need to educate your child about sexual health and protection. Work with teachers and school counselors to make sure your child benefits from instruction provided in the schools. Local offices of the state developmental disability program and centers for independent living also may offer opportunities for education and training in this area. Caregivers can use strategies such as showing examples and nonexamples, role-playing, and talking about scenarios to teach about biological and reproductive health, health and hygiene, healthy and unhealthy relationships, and advocacy and self-protection. It is important for your child to understand appropriate touching and

interaction and in what situations people can engage in intimate behavior. A variety of parent training modules are available through http://disabilityworkshops.com/.

9. ***Support the development of socialization and friendship skills.*** You can prepare your child to interact with others by teaching social skills and providing broad opportunities, such as the following:
   - Provide opportunities for your child to socialize and interact with peers. Find opportunities for social activities within the local community, such as recreation center activities, scouts, or sports. School districts and communities across the country offer unified sports programs where peers work with children with disabilities (e.g., Best Buddies, Special Olympics).
   - Teach skills such as taking turns, beginning and ending conversations, determining appropriate topics for conversation, identifying emotions, recognizing the feelings of others, and decoding body language and facial expressions. Talk about and share pictures or examples of different interactions where individuals are showing emotion and reading body language.
   - Teach social skills in the settings where they are most likely to be used (e.g., in a restaurant, on the playground, in school).
10. ***Provide opportunities for practicing self-determination skills in home and community.*** Create the following opportunities for your child to practice making choices in diverse settings:
   - Provide choice and control in the home environment. For younger children, set up opportunities to choose toys or show preferences for food or what to wear. For middle and secondary students, provide opportunities for choices around use of free time, social opportunities, and participation in IEP meetings.
   - Promote self-confidence and self-awareness through participation in diverse settings (e.g., day care, community events, faith-based organizations) and discussions about the abilities and challenges of different populations.
   - Teach and model problem-solving and self-advocacy strategies, using media and books to illustrate the process or examples while offering support when necessary.

## RECOMMENDED RESOURCES

**Websites**

http://www.p2pusa.org/

Parent to Parent USA (P2PUSA) is a national nonprofit organization committed to promoting parent-to-parent support across the country.

http://www.lifecoursetools.com/planning/

The Charting the LifeCourse Framework was created by families to maximize person-centered planning strategies.

**Books**

Baker, B. L., & Brightman, A. J. (2004). *Steps to independence: Teaching everyday skills to children with special needs* (4th ed.). Baltimore, MD: Paul Brookes.

This book provides parents with proven strategies for teaching their children the life skills they'll need to live as independently as possible.

Heineman, M., Childs, K., & Sergay, J. (2006). *Parenting with positive behavior support: A practical guide to resolving your child's difficult behavior*. Baltimore, MD: Paul Brookes.

This handbook offers parents easy-to-follow guidelines for the direct application of positive behavioral interventions and supports (PBIS). Exercises and worksheets help parents easily track their child's progress, and three illuminating chapter-long case studies walk parents through PBIS and show them how this process can transform family life.

**Related Helping Handout**

Using Praise and Rewards Wisely: Helping Handout for School and Home

## REFERENCES

American Association of Intellectual and Developmental Disabilities (AAIDD). (2012). *User's guide to intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: Author.

Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2013). Mindfulness Based Stress Reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: a community-based approach. *Journal*

*of Child and Family Studies*, 1–11. doi:10.1007/s10826-013-9836-9.

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). The State of the States in Intellectual and Developmental Disabilities, Emerging from the Great Recession. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Braddock, G., & Rowell, J. (2011). Making Homes that Work: A Resource Guide for Families Living with Autism Spectrum Disorder+Co-occurring Behaviors. Creative Housing Solutions and Rowell Brokaw Architects.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N., & Lawrence, M. (2007). Examining individual and ecological predictors of the self-determination of students with disabilities. *Exceptional Children*, *73*, 488–509. doi:10.1177/001440290707300406

Simonsen, M., & Neubert, D. A. (2013). Transitioning youth with intellectual and other developmental disabilities: Predicting community employment outcomes. *Career Development and Transition for Exceptional Individuals*, *36*, 188–198. doi:10.1177/2165143412469399

Sugai, G., Horner, R. H., Dunlap, G., Hieneman, M., Lewis, T. J., Nelson, M. C., … Ruef, M. (2000). Applying positive behavior support and functional behavioral assessment in schools. *Journal of Positive Behavior Interventions*, *2*, 131–143. doi:10.1177/109830070000200302

Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *American Journal on Mental Retardation*, *100*, 632–642.

Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities*, *38*, 131–144.

## ABOUT THE AUTHORS

**Frank J. Sansosti, PhD, NCSP,** is assistant director of Lifespan Development and Educational Sciences and professor and coordinator of the school psychology program at Kent State University. His primary research and professional interests focus on the provision of best practice instruction and intervention to students with autism spectrum disorder (ASD) and related low-incidence disabilities. Such work has focused on evidence-based principles of effective school-based interventions, the use of technologically derived instruction, and effective transition planning and service delivery. Dr. Sansosti is acknowledged for his hands-on approach for extending research to practice.

**Darlene Unger, PhD,** is professor of special education at Kent State University and a researcher with the Center for Disability Studies. Her clinical and instructional experiences reflect the delivery of transition-focused education services for youth with autism and intellectual disabilities. Dr. Unger has coordinated federally funded research and training projects to improve transition service delivery and employment outcomes for individuals with disabilities through supported employment and business and rehabilitation partnerships. Dr. Unger has served on the steering committee for Think College in Illinois and is president of the Council for Exceptional Children's Division of Career Development and Transition.