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## “Why Aim for Independent Living?”

### YOUR CHILD’S REALITY NOW AND IN THE FUTURE

“Jamie, time to wake up,” Taylor whispers to her son for the third time this morning. He grumbles and rolls over. She picks him up and places him on his feet, knowing if he’s not up on his own by now, she must intervene. He rubs his eyes and sits on the floor. Taylor says, “Time to potty,” but Jamie stays on the floor until his mother lifts him to standing again. She points toward the bathroom and says firmly, “Go potty.” Jamie walks to the bathroom still rubbing his eyes and yawning. He uses the bathroom and returns to his bedroom. Taylor cocks her head to one side and taps his shoulder to get his attention. “I didn’t hear the flush. Go flush the toilet and wash your hands.” Jamie goes back and flushes the toilet before returning. She sends him back again to wash his hands. He does as he’s told, then returns with wet hands that don’t smell like soap, and water down the front of his pajamas. Taylor sighs and walks him back into the bathroom, points at the soap, and says, “Use soap,” before turning on the faucet. She then takes Jamie’s hands, places one under the pump and one on top and presses down until soap comes out. Then she rubs Jamie’s hands together under the faucet. Once he’s done and she follows him back to his room, she points to the outfit that she has laid out on the bed. She says in a tired voice, though the day has only just begun, “Time to get dressed. It’s picture day today.”

Sound familiar? The morning routine can be one of the most demanding parts of the day. And the rush to get everyone to school and work on time adds pressure none of us need. The reality is, your days are long. Hectic. Sometimes they feel monotonous. You may feel like a broken record having to

give the same directions and reminders day in and day out to your child with a developmental or intellectual disability. You manage to get your child off to school, but your duties don't end there. Let's meet Mark, whose 12-year-old son, Andy, has autism.

The phone rings as Mark types up a proposal at work. It's Andy's speech therapist with an update from his latest assessment. She confirms what Mark feared—Andy's social pragmatic language skills are still significantly delayed for his age, and he is struggling to engage with his peers during academic and social time. As Mark's heart sinks, the therapist recommends they look into a social skills group at the local university. She reminds Mark that helping Andy improve his communication skills will probably decrease the number of arguments he is having in class. This is a big goal for his individualized education program (IEP) team. Mark jots down the name of the professor in charge of the groups, knowing this means more research for him to do and yet another appointment on both Andy's and Mark's already overcrowded calendars.

Mark is still processing this news when his cellphone buzzes five minutes later. It's Andy's teacher, telling Mark that Andy had a difficult morning and a conflict with his group during math. Andy has calmed down now but refuses to rejoin class to finish the day's lessons. Mark glances wistfully at his coworker Jane, who is arranging a new set of framed photos of her two neurotypical children on her desk. The oldest just left home for college, and the youngest, the same age as Andy, made it to the state competition for speech and debate. "I'll be there in 20 minutes," Mark tells the teacher reluctantly.

Scheduling can be a nightmare. And if you have other children, you are likely over your limit managing pickups, drop-offs, dentist appointments, sports practices, games, competitions, lessons, family events, and therapy sessions. It can be overwhelming and nonstop. Your responsibilities may not end even after your child graduates from high school or a transition program. For many families of children with disabilities, these responsibilities can be lifelong. Let's meet Mariela and her 19-year-old daughter Janie, who has a rare genetic disorder and an intellectual disability.

"Let's do the checklist," Mariela tells her daughter. "Wallet, phone, keys, and lanyard," replies Janie. "That's right, and don't forget to remind the

manager that you need to leave at 2.” “Mommmmm, I know, it’s in my calendar app. Geez.” Mariela smiles at her daughter’s slightly sarcastic response and accompanying eye roll. Janie knows the drill. She’s been working at the local grocery store in the bakery for almost three months now and has the routine down pat.

When Mariela goes to pick Janie up a few hours later for her appointment, she’s surprised to see Janie in tears. Janie tells her that her boss had forgotten to get coverage for the second half of her shift, so when she reminded him about her appointment, he had asked if she could stay later. Mariela froze. Two of Janie’s big triggers are schedule changes and missed appointments. Janie said that it took her “a long time” to calm down and that she was “stuck” on missing her appointment. She said, “Mom, I just kept telling him that I have to go. I have to go. But he didn’t listen to me.”

On the drive to the appointment, Mariela panicked. She knew she was catastrophizing, but all her worries about Janie’s future, along with a long list of what-ifs, came flooding into her mind. What if Janie was fired? This was the first job she’d been able to keep. She loved her coworkers, and the schedule worked great with other family obligations. Would the store have eventually called the police if she hadn’t calmed down? Should Mariela have talked to the manager instead of having Janie do it herself? She wanted Janie to be independent, but that seemed so far away still.

For all parents, the worries don’t end when their child graduates from high school and gets a job. But for parents of children with disabilities, those worries are often bigger and more complex, as is their role in their child’s life. Many times, parents and family members continue to have an outsized presence in their young adult and adult children’s lives. This role may include advocacy, transportation, guardianship, decision making, and other types of support.

Indeed, you have a lot on your plate. You’re juggling more than most people, and you may be worried you’ll be inundated with the same obligations the rest of your life. We have seen firsthand how these worries can wreak havoc on families in the short and long term.

Your worries are not unfounded. The research paints a dim picture of what a child with an intellectual or developmental disability has to look forward to as an adult. In our work, we see clearly how independent living skills promote healthy lifestyles and thriving families. On the flip side, we also witness what happens when families neglect to teach their child with intellectual

or developmental disabilities independent living skills while they are still young. When these children turn into young adults who still lack these skills, the effects can be devastating. This is true for all of us, but it is particularly impactful for children with intellectual or developmental disabilities and their families. We share this information with you not to discourage you, but to provide an honest depiction of what your child's future could hold if the proper supports are not put in place now. Let's look at what the data tell us, so that you can understand the full context in which you are operating.

## What the Research Tells Us

In general, people with *autism spectrum disorder* (ASD) and an *intellectual disability* (ID) are doing particularly poorly when they exit high school or the K–12 system. Longitudinal data on adults with ASD find that about half (49.3%) have poor outcomes related to social involvement (friends and relationships), competitive employment, and independent living (Mason et al., 2021). One study found that adaptive skills are an important factor that influences living situation, employment, education, and physical health outcomes (Forbes et al., 2023). So, what this tells us is that teaching children adaptive skills using task analysis may have a significant impact on their future success.

In the next sections we present real-world scenarios of what families face every day while helping their children navigate the world of independent living. We present these illustrative stories alongside current research detailing long-term outcomes for people with ID across domains.

### Lack of Services and Service Providers after Graduation

Rosa crossed her fingers as she called the seventh therapist on her list. Her son Raul, a 19-year-old with autism and an intellectual disability, was struggling with inappropriate behavior in his dayhab and was on the verge of being removed from the program. Due to the seriousness of the behavior, his social worker suggested finding a behavior analyst (this may refer to a Board Certified Behavior Analyst [BCBA] or licensed behavior analyst [LBA]) to take on Raul's case. Rosa had contacted so many providers, she basically had a script memorized. Yes, they had insurance. No, they could not afford private pay. No, he was not in school, so there was no school

district to foot the bill either. Yes, he needed support in the community. No, a clinical setting would not work for him. Thus far everyone she spoke to was either booked, private pay only, or only worked with young children. She knew it wouldn't be easy to find a provider, but she didn't think it would be this tough.

The dayhab program was fine, but essentially amounted to day care for adults. Raul didn't really like going there. It was only for two days a week, but Rosa needed those two days so she could work her freelance job and take care of things around the house. It was up to Rosa to create Raul's programming for the rest of the week. They went to the movies on Mondays, shopped together on Tuesdays, and had Special Olympics on Thursdays. This wasn't enough. Raul needed more, and she was worried that his behavior would mean she'd be looking for another dayhab program soon too. Rosa sighed and dialed again.

Many people with disabilities and their families feel that leaving the K–12 system is like falling off a cliff in terms of services, community, and opportunities. There are also precious few resources at the local, state, and federal level for adults with ID and ASD, which becomes particularly stressful if a family cannot afford to pay for private services. The system is “ill-prepared and underfunded” and presents a “looming crisis of unprecedented magnitude for adults with autism and their families” (Gerhardt & Lainer, 2011).

Many practitioners only work with younger populations. Therapists are also not transition specialists and may not be familiar with the resources available to young people with disabilities after they graduate. Insurance may be unwilling to cover services that had been previously provided by school districts or transition programs. These issues may seem far away, but most parents report that the old adage of “the days are long, but the years are short” really holds true and that their children arrive at adulthood and transition more quickly than they realize. This is our inspiration for talking about these issues early and often with parents of children, even before adolescence.

## **Postsecondary Education**

Jordan had always been interested in cars, so his mother, Maya, started to research mechanic and car tech programs in their area. Unfortunately, those programs required a regular diploma from an accredited high school or a GED for their applications, and Jordan had only received a certificate of

completion for an alternate diploma. The high school that Jordan attended had a vocational feeder program for mechanics, but Jordan wasn't eligible to participate because he was in the Life Skills program and the mechanics teacher wasn't willing to work with the Life Skills teacher or Maya.

Maya was incredibly frustrated with the high school and with Jordan's options for education after graduation. He attended school until he was 21, and then Maya felt like they'd been dumped by the school system and his transition program with no plan in place. He'd been added to waiting lists for day programs and Maya was left to organize everything for his schedule and his daily life. She began looking at the inclusive higher education program at the local university, but soon realized that the price tag was far too much for them. She wasn't sure what to do now.

The *Individuals with Disabilities Education Act*, or IDEA, does not apply to colleges, universities, or postsecondary education of any kind. So, the right to access education after high school is not guaranteed. While students are still covered by *Section 504 of the Rehabilitation Act of 1973* after high school, those protections are very limited when compared with IDEA. Section 504 forbids discrimination within any organization that accepts federal funding, but only allows for accommodations that don't create an "undue burden" or "fundamentally alter" an activity. While there are increasing opportunities for postsecondary education through inclusive higher education programs, there are currently only about 300 of these programs nationwide, with very limited capacity (<https://thinkcollege.net>). Some programs receive 10 times more applications than the number of students they can admit. Many of these programs also require students to attain minimum levels of proficiency in reading and math, the ability to be left unsupervised for several hours or even 24 hours at a time, and mastery of basic safety behaviors like being safe on a college campus or crossing streets. Many young people with ASD and ID simply do not qualify for inclusive higher education programs, and even if they do, it does not guarantee acceptance into a program due to the limited number of spots available.

Another factor is the cost. There are now more options for funding for postsecondary education through state-level workforce or vocational rehabilitation programming. However, these concessions are hard won by parents advocating their state programs and lobbying for new laws allowing for this funding to be used. These programs also may not qualify students for loans

or grants through *Free Application for Federal Student Aid*, or FAFSA, as it's commonly known. The steep cost is often more than families can afford, particularly since most families did not know these programs existed when their children were young, so they missed out on opportunities to save.

There are also vocational training programs for jobs such as cosmetology, welding, or health care roles such as nursing aides, but these require students to have obtained a high school diploma, complete a rigorous certification process, take written and practical exams, and participate in internships. The coursework and exams needed to obtain these certifications are usually fairly rigid and therefore do not lend themselves to accommodations. If students are accepted, the challenges continue; students must keep up with the pace of coursework, and while some instructors may be willing to provide supports, these would be on an individual basis and are not guaranteed. These programs also come with a hefty price tag that must be paid up front or through loans. Either way, these programs may be out of reach for many families.

## **Social Connections or Friend Networks**

Dori clenched her phone in her hand. Her friend Emily hadn't texted her back. Dori texted again, for the 30th time. She'd also called, sent Instagram messages, and tried to FaceTime Emily. Dori has Down syndrome, and seeing and talking with her friends was important to her, especially since she'd left her transition program at the high school and her social connections had dwindled. She knew she shouldn't text and call too much, but she just couldn't seem to help herself. When her mom knocked on her door and came to sit on her bed, she knew she was in trouble. Molly, Dori's mom, said she wasn't "in trouble" but let her know that Emily's mom had reached out to her. Molly told her that Emily didn't want to talk to her and so she had blocked her number for a while. Molly said that Dori needed to respect that boundary. Molly told her, "Dori, sometimes silence is a no. Sometimes no response from someone is a no. You need to listen to that too. Emily went off to college and she's very busy. She can't talk to you every day like she used to. We'll have to find some other friends for you to talk to." Molly held Dori as she cried.

For young people and adults, friendships and social networks are critical to quality of life and a feeling of connectedness to a community. The social picture of people with ASD and ID in adulthood is rather bleak, with many

reporting high levels of loneliness, depression, and dissatisfaction with their social networks (Mazurek, 2014; van Asselt-Goverts et al., 2015).

Research shows that people with ASD and ID also score lower on quality-of-life assessments overall (van Heijst & Geurts, 2015). Some of this is due to limited social and friend networks. People with ID have fewer nondisabled friends than those with physical disabilities, even though people with ID reported participating in more community activities. Most of their social network is made up of caregivers and family members (Lippold & Burns, 2009). One study found that only about half (52%) of older adults with ID had a best friend. A quarter of those with a best friend listed a family member or staff member as their best friend (McCausland et al., 2021).

On a positive note, a literature review found that social skills instruction, informal support, and involvement in support groups increased quality of life for people with ASD (Tobin et al., 2014). People with disabilities deserve well-rounded lives that they feel satisfied with. While social skills are often overlooked as adaptive skills, they have a significant impact on overall quality of life. This book does not address social skills directly, but it would be very difficult to engage in many social activities without the foundational adaptive skills we cover in this book, like listening and responding to verbal interactions, following a routine, and maintaining good hygiene. These are the first place to start building social skills, and many of these are what we call *prerequisite skills*, or skills you need to have first before you can begin to learn a higher-level skill. In practical terms, it can be very hard to make friends if you can't shower, put on deodorant, brush your teeth, and leave the house.

## Transition Services

Ben was sure he was ready to work. He had three different internships and four places he regularly volunteered, including his church. He had letters of recommendation, lists of people who would serve as references, a résumé, and a clear idea of what types of jobs he liked: customer service and sales, particularly focused on the outdoors. He had lost count of the number of mock interviews he had completed. What he didn't have was a clear idea of how to make his ideal job, where he wanted to live and how (in an apartment with a roommate), relationships (both friends and romantic), and his finances work out. While most people use the time between high school and adult life to figure these things out, Ben was expected to do this right



away once he left high school. He felt very confident about employment, but the rest of the picture was still blank for these other important areas of his life.

Many families do not receive appropriate transition support and planning even though it is required for all students with IEPs. Even students who receive transition services may not leave high school and transition programs with the skills needed to live on their own. Transition supports and services, including vocational rehabilitation, tend to focus primarily on employment outcomes. While future and current employment are important, they are only one piece of the independent living puzzle. Most families are faced with the reality that there are few options for continued services for their child and family, even in the states with the best infrastructure and programming.

The truth is that many students with disabilities graduate or age out of services and their only option is to continue living with their parents for the rest of their lives because they lack the skills to live independently. Many are completely disconnected from services, have no employment or place to go during the day, and very few if any social connections, community involvement, or hobbies. They graduate to their parents' couch. It's one thing if someone chooses to live a life in which they contribute to their family home, take responsibility for household chores, and are active participants in their communities after they graduate or leave school. This may be a wonderful future and exactly what that person and their family wants. The difference in these two situations (staying at home with family because it's what you want versus being forced to stay at home because of lack of options) is *choice*.

Planning for your child's independence now is an excellent first step toward giving them the broadest range of choices in education, employment, living situation, relationships, and anything else you can think of. When we limit a child's independence now by not teaching them the skills they need and fading ourselves (parents and professionals) out of these daily routines, we limit their future choices and options.

## **Employment**

When Esther took her daughter Cam for a job interview at the local gym, she was sure that she and the vocational rehabilitation specialist had planned for everything. Cam was showered and dressed appropriately. She

had copies of all her documents, had completed the online application process, and had role-played all the common interview questions. And it went great! Cam got the job!

The initial excitement quickly wore off though, as the real problems didn't start until Cam finished training. She struggled with what to do during "down time" during her shifts, taking directions from bosses she didn't know, and receiving any corrective feedback from her coworkers or boss. One day, she told her regional manager that she wouldn't do one of the main tasks of her job, which was cleaning equipment returned by the gym guests. That was write-up number one. A string of write-ups followed because the more her bosses tried to work with her, the more Cam refused to do the tasks. Esther was beyond exasperated, and then it hit her. This was something Esther couldn't fix. Cam was an adult with a job and the job didn't have to accommodate her. Esther couldn't advocate and help in the ways she used to in high school. There was no IEP team to meet with, no head of special education to petition, and no vocational rehabilitation therapist to intervene. Cam was really on her own to sort this out.

Even when people with disabilities can find employment and maintain a job, there are many barriers to overcome. These include laws and regulations that allow for them to be paid less than minimum wage (yes, that's still legal in many places in the United States; Fair Labor Standards Act, 1938/2008), not to mention unconscious bias or overt discrimination based on their disability (U.S. Equal Employment Opportunity Commission, 2024).

Research has shown that six years after graduation, only between 17 and 39% of adults with ID are employed in competitive integrated settings. Competitive employment means that they competed against typically developing people during the application process and are being paid the standard wage, and integrated means they work alongside typically developing people. Additionally, of those few who are employed, only 59% make more than minimum wage. While there is nothing inherently wrong with a minimum-wage job, minimum wage is not a living wage in most places in the United States. So, what about the rest of the adults with ID? They are either employed in sheltered workshops or in segregated environments away from their typically developing peers, where they make less than minimum wage, or they are completely unemployed (Qian et al., 2018).

People with ASD are even less likely to be employed than those with just ID, with only 25% employed at all and only 6% competitively employed

(Dudley et al., 2015). The good news is that one study found that more independent daily living skills (along with other factors) gave adults with ASD and ID significantly higher likelihood of sustained community employment (Chan et al., 2018).

## Independent Living

Kevin, a 28-year-old with autism, was excited to move into his first apartment. He had worked with his family, case manager, state funding programs, and roommate to make this happen, and move-in day was finally here! This was going to put all he had learned about being independent to the test. He'd have to keep his apartment clean, shop for groceries, do his own laundry, and get to work on his own. This means he'd need to use all the strategies for self-management he'd been taught, including breaking big and often overwhelming tasks into bite-sized parts, and then completing them one by one. Both his family and his roommate's family agreed to help them by checking in regularly, especially in the first few weeks as they learned the ropes.

One of Kevin's first obstacles was a common one for someone living with roommates for the first time: dishes left in the sink and taking out the kitchen trash. He'd used his social skills to schedule a time to talk with his roommates, come up with a chore schedule for taking out the trash, and make new rules about the dishes. Crisis averted! Kevin knows there will be other challenges, but he has the support and independent living skills to address them when they come up.

Kevin was very fortunate to have received the training and education he needed to make this big achievement happen. He was also very lucky that his parents encouraged him to do things for himself—he had to admit that while he was learning to do things on his own, he wasn't always so happy about it. In the end, Kevin is glad that his parents insisted that he do things independently. Getting to this place in his life had been so much work, but the excitement he was feeling made it all worth it!

Another area of need for people with ASD and ID is living on their own or with roommates (natural supports). Studies show that by age 23, only between 5 and 19% of young adults with ASD live independently (Forbes et al., 2023; Roux et al., 2015). This is the lowest rate of independent living across disability categories. Conversely, that means between 81 and 95% of this population is living at home with family or in a facility.

One thing that makes living by yourself or with roommates possible is being able to prove financial independence, which is a struggle for people with ASD and ID. They are less likely to have a bank account or credit card, with many remaining under their parents' guardianship, which means they do not have full control of their financial decisions (Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services, 2019; Sanford et al., 2011). The vast majority of those with ASD and ID are also making less than \$25,000 a year (Sanford et al., 2011). They may also be limited in how much money they can have in a savings account because it may affect their SSI (supplemental security income) benefits. SSDI (social security disability insurance) also limits how much money a person can gain from work, putting people with disabilities in potentially precarious financial situations.

People with disabilities need as many practice opportunities as possible to learn and maintain skills—so they can earn a living wage, manage their finances, and secure a place to live independently. Starting early and practicing often can help address the deficits in independent living skills that will impact your child's life when they transition into young adulthood, including their ability to hopefully one day live independently.

## What's Your Situation?

You've just read snapshots of several families' daily lives. Their stories may be different from or similar to your situation. Some families may be farther down the road than you, but perhaps you can imagine your future self in their shoes, up against the scary statistics of our present moment. The question is, are you willing to work more effectively now to invest in an independent future for your child?

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### ACTIVITY: Your Efforts

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Spend some time pondering the following questions. You may come up with answers as soon as you read them, but spend a day or two thinking about these questions while you are going through daily routines with your child.

Some of your answers may change, or you may see things while engaged in a routine with your child that you didn't think of initially.

- What do your child's morning and bedtime routines look like?

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- What are the things you have to say and do over and over again to help your child get through the day? \_\_\_\_\_

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- In what ways do you need to help your child that are above and beyond what you would normally need to do for a neurotypical child? \_\_\_\_\_

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- How often do you have to be present, just to make sure your child is safe? \_\_\_\_\_

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### ACTIVITY: What If?

Now we'd like you to ponder what would happen (or what likely has already happened) if you were sick in bed. Not sniffles and sneezes, but can't-move-body-ache-fever-misery sick. How would your child fare without you being there in the morning?

	Yes, my child would do this if I did not help them	No, my child would not do this if I did not help them
Would they make it out of bed on time?		
Would they choose school-appropriate clothes to wear?		
Would they choose weather-appropriate clothes to wear to school?		

	Yes, my child would do this if I did not help them	No, my child would not do this if I did not help them
Would they have all the important pieces of clothing on (underwear, shirt, pants/skirt/shorts, socks, and shoes)?		
Would all pieces of clothing be put on correctly (shirt, underwear, and pants/skirt on right-side out and front side forward, and shoes on correct feet)?		
Would they brush their teeth for two minutes using toothpaste?		
Would they wash their face with soap and/or a washcloth?		
Would your child wipe themselves after using the toilet?		
Would they wash their hands thoroughly with soap after using the toilet?		
Would the washing and wiping be done to your standards?		
Would they eat breakfast?		
Would that breakfast be up to your standards for nutrition and meet your child's dietary needs?		

We aren't asking you to contemplate this to upset you, but rather to illustrate the massive degree to which your child relies on you for things as simple as getting dressed and brushing their teeth. Your goal is to teach your child to be more independent. Throughout this book we're going to provide you the knowledge and skills to help support your child as they move toward independence. It will take time, but starting is the first step, and the work gets easier when you stick with it over time. We'll lead you through activities, give you some new vocabulary, and ask you to examine your child's world with a new perspective. Let's get started!