

RIGHTS. We—people with disabilities and family members—have them. Technically, these might be entitlements to services, benefits, or legal protections, but many use the generic term RIGHTS when referring to government-mandated early intervention (EI) and early childhood education (ECE), special education, respite care, employment/vocational-rehabilitation (VR), housing assistance, and other services.

Many people with disabilities and their families may be pleased with the RIGHTS afforded under federal and state laws. Yet many others are frustrated and angry by the poor quality and/or lack of relevant services. In either case, there are many family members and people with disabilities who seem to see the fulfillment of their RIGHTS as *the most important goal in their lives*. For some it's an almost frenzied zeal—like cheerleaders, we exhort our side to “fight and win.” For others it's a quiet, stealth-like determination that consumes our waking hours. The intended outcome—a person/family receiving all benefits and RIGHTS afforded under state and federal policies—may occur, and we then feel we have achieved success. Some of us even view this as a “victory”—as if we've been fighting a war and our side finally “won.” Later, we may be shocked to learn the victory was short-lived. For when moving from one service system to another (EI to ECE to special ed to adult services, for example), we may have to start all over again. Success in one venue doesn't guarantee success in the next!

So we may temporarily achieve the intended outcome: getting all our RIGHTS. In the process, however, a variety of *unintended* consequences sneak into our lives, some of which we're not even aware!

The quest for RIGHTS or services may leave us frustrated, angry, and tired. We don't treat ourselves or our loved ones very kindly when there's no time or energy left to have fun, relax, read a book, go to a movie, be with family, enjoy peaceful dinners, and more. A

The “Right” to a Normal Life

Revolutionary Common Sense
by Kathie Snow, www.disabilityisnatural.com

positive outlook on life can devolve into a permanent, negative, pessimistic daily struggle against our collective “enemies” in the system. Our personal identities become cloudy as we assume the “victim” mentality. The list of

unintended consequences is varied and endless. Still, many of us relentlessly pursue our RIGHTS, believing that's where we'll find the gold at the end of the rainbow.

But what about the “right” to a normal life—a REAL LIFE—instead of a life as a client, recipient, patient—a “special” life? In our zeal to address the “problems” of a person's disability and ensure he receives all his RIGHTS, we often overlook the more important and valuable opportunities: those typical and ordinary elements of daily living that weave the fabric of a wonderful life. Yes, we need to ensure that individuals with disabilities enjoy the same rights of citizenship as other Americans, but in the process, we dare not deny them the opportunities to be fully human!

Does a two-year-old have the opportunity to be a “terrible two” and say “No!” to everything? If she's unable to experience this powerful and important milestone because she hasn't yet acquired speech, she needs a communication device or some other form of effective communication so she can assert herself the way other two-year-olds do. If she doesn't acquire the power to communicate “no” as a child, how will she protect herself when she's older?

Too many children, however, are denied the opportunity to communicate at the age-appropriate time (which prevents them from leading normal lives). Parents, therapists, or others believe that giving a child a communication device will prevent the child from learning to speak! There is no proof to this assertion; it's someone's opinion. And, yes, some children may never acquire oral communication—all the more reason to provide an alternative way to communicate. Conversely, I have known children who, as two-year-

I am not afraid of storms for I am learning how to sail my ship.

Louisa May Alcott

2 - *The “Right” to a Normal Life*

olds, used communication devices, signing, and other methods, and as they acquired oral communication, stopped signing or discarded their devices. Alternative forms of communication did not get in the way of their learning to speak.

Does a toddler have the opportunity to “run away” from Mom and Dad? To come and go as he pleases—to explore and master his environment? If he can’t because he’s unable to walk, he needs a power wheelchair or other form of *independent* mobility so he can learn and grow from the rich environments of his bedroom, his home, his yard, and his community. Independent mobility provides more than movement from point A to point B: it promotes self-determination and self-esteem, and enables a child to play with others, be a big brother, help around the house, take control of his own life, and so much more! But many children are denied independent mobility, for the same reasons others are denied communication devices. When this occurs, they are also being denied the right to experience typical development and typical lives.

Is a child with a disability given an allowance? Expected to help around the house? Taught how to use the phone? Have a pet he’s responsible for? Wake up to an alarm clock? Make her bed? Help with cooking or cleaning up after a meal? Have birthday parties with friends (not just family)? Select presents for others? Is the child expected to participate in and experience the traditional, ordinary, typical activities of her brothers, sisters, and similar-aged children? Is she expected to achieve an academic education which will enable her to attend college, vocational school, and/or be employed in a real job? Do we expect the child to leave home one day, live on her own, get married, and lead a REAL LIFE as an adult? When we don’t encourage and provide typical experiences (and have high expectations) we’re robbing a child of the “right”—the opportunity—to lead a normal life.

Parents may think it’s the child’s disability diagnosis that precludes their child from participating in the ordinary routines of childhood. But in my experience, it’s not the disability itself, but the *lack of tools*—a communication method, independent

mobility equipment, other assistive technology devices, environmental accommodations, behavior supports, or anything else—that prevents a child from enjoying typical experiences. Simultaneously, we may not recognize the *value* of these ordinary experiences because we’re too focused on rights, services, therapies, or entitlements.

I’ll never forget the morning I repeatedly yelled at then ten-year-old Emily to get her room cleaned up once and for all. Eight-year-old Benjamin wheeled over to me, and in a nervous, but hopeful voice, asked, “Mom, do you want *me* to clean up *my* room, too?” With this whack on

the side of the head, I realized I had not been giving Benj enough opportunities to be responsible, and I had not been treating him like his sister was treated! “Yes!” I replied sternly. “Get in there right now and don’t come out until your room is clean!”

With a big grin on his face, he wheeled to his room and put some of his toys in the bins on his dresser. Then, near tears, he wailed, “Mom, I don’t know where some of this stuff goes!” How could he? *His dad or I had been doing this for him.* What a lesson from a child! Things changed after that. Later, Benjamin often whined about having to clean up after himself. What kid doesn’t? This, too, is a typical, ordinary, valuable childhood experience!

What about today’s adults? As children, many were not *allowed* to experience typical opportunities, so they didn’t learn “the basics.” As adults, many are still not being allowed to participate in ordinary experiences or assume typical adult responsibilities.

It seems that many adults with developmental disability labels are “placed” in group homes and other “special” living arrangements because, as children they were not expected to succeed, not allowed to participate or learn from typical activities, nor be responsible for themselves to the greatest degree possible. Thus, as young adults, they’re believed to be incompetent, so others continue to “take care” of them. On the other hand, children with disabilities who were raised in an environment where they were expected to lead normal lives (with accommodations, supports, etc.), become adults with disabilities who lead normal lives (with accommodations, supports, etc.).

**Life is a process of becoming,
a combination of states we
have to go through.
Where people fail is that
they wish to elect
a state and remain in it.
This is a kind of death.
Anais Nin**

Is an adult with a developmental disability expected to explore and decide what type of job he wants? (And do we believe him, trust his instincts, and respect his dreams, or do we dismiss his ideas as “unrealistic”?) Does he have the opportunity to attend college, trade school, or pursue other avenues to help him learn the skills needed for his dream job? Is he expected to know—or to learn—how to find a job the way people without disabilities find jobs? Is he expected to be responsible for his own money? Does he have the opportunity to determine and/or find his own place to live, with the roommates and supports of his choice? Is he able to get the naturally-occurring help that’s available from family, friends, neighbors, and coworkers, or is he dependent on service providers?

The presence of a disability diagnosis is not a barrier to leading a normal life. No, the barrier exists in our minds—in our beliefs about the person who has been labeled and the actions we take based on these beliefs.

**You cannot create experience.
You must undergo it.**

Albert Camus

We may not believe a child or adult with a disability is physically or mentally capable of doing many “normal” activities. This is nothing short of prejudice. We prejudge a person based on the label, or we make decisions without considering other possibilities and options, including the use of natural supports, modifications, and/or assistive technology.

At age 22, Casey still lives at home and attends a day program. She has never worked and her mom, Martha, says she never will: “Casey can’t talk and she’s low-functioning. She can’t do what other people do.” When asked why Casey doesn’t have a communication device, Martha says they tried one year ago, it didn’t work, and that’s that! She’s not interested in exploring other devices or other forms of communication for her daughter because Martha says she “knows” what Casey wants. Martha has made Casey dependent on her, and under the current circumstances, Casey’s opportunities for success are limited. But with assistive technology, supports, and/or modifications, Casey could probably communicate her wants and needs, and move her life in the direction of her choosing. Without those tools,

she’s stuck—imprisoned in environments she has no control over. Casey’s disability isn’t a barrier to her success, but her mother’s attitudes and beliefs are.

Fear, worry, or selfishness may drive our actions. Sonja says she must feed ten-year-old Jason at every meal because, “He can’t hold a fork or spoon very well.” She refuses to let Jason feed himself finger foods because, “He’s a messy eater and I’d probably have to change his clothes.” What about tucking a napkin in Jason’s shirt, spreading another on his lap, and helping him learn to clean his face and hands with a wet wipe? Sonja explained, “But I can feed him faster than he can feed himself.” Is Sonja afraid Jason will fail, so she’s unwilling to let him try, or are *her* needs more important than her son’s? How can Jason have real experiences when his mom believes cleanliness and speed are more important than Jason learning to care for himself? Can we afford

to allow *our* fears or needs to get in way of another person’s opportunities to live and learn in the real world and lead a normal life?

A person with a disability may not do things in the same way, with the same speed, using the same tools, and so forth, as others. Still, his experiences as he does things “his way” are no less valuable. Who wrote the rules on the “right way” to do anything, anyway?

To ensure children and adults with disabilities enjoy the ordinary, typical, *growth-producing* experiences most people take for granted, we may need to: listen more carefully, with our ears, our eyes, and our hearts; develop new attitudes; be more creative in our thinking; and provide assistive technology devices, supports, modifications, extra time, and so forth, in natural, inclusive environments. Legal rights, entitlements, and services may be important, but their value pales in comparison to the rich, varied, and collective day-to-day experiences that are the foundations of living a normal life.

What would you want if it were you? Isn’t it really that simple?