NO RESPONSIBILITY? NO REAL LIFE.

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

Personal responsibility. When we have it, we're in control of our lives and we live with the consequences of our actions. We experience success and failure, and learn in the process. Our lives are our own. When we don't have personal responsibility, we're dependent on others, which can lead to anger and frustration—on the one hand—or learned helplessness and apathy, on the other. The successes or failures we experience are the result of someone else's actions; we learn little, and our lives are not our own.

In the Real World, taking personal responsibility is part and parcel of maturing from a child into an adult. But this natural occurrence gets turned on its head in Disability World, to the detriment of people with disabilities, to their families, and to our society, as well.

During a break at a conference of adult service providers, "Sonia" (a Home Health Manager) described her responsibilities: making doctor's appointments for the residents of a group home, taking them to these appointments, making sure they took their medicines, and similar tasks. During the presentation I had just given, I stressed the need to presume competence in people with disabilities. Sonia excitedly said her agency was doing just that (presuming competence) at the group home: "We'll be writing a new IHP [Individualized Habilitation Plan] on Monday for one of our clients, and then *she'll* be responsible for taking her own medication! Isn't that great?" I agreed that it was, and asked about the other people at the group home: could they be responsible for making their own doctor's appointments, taking their own medications, etc. "No, that wouldn't work—they can't tell time!" I offered several suggestions, including providing the people with digital watches or clocks with alarms and other goodies, but Sonia repeatedly shook her head and indicated nothing would make a difference. "Nope, they're not responsible enough." But did anyone ever *try* to help these individuals become more responsible—and try, try, again, if necessary?

Responsibility is the price of freedom.

Elbert Hubbard

"Tom," the father of a young teenager with a disability, is frustrated that his son, "Andy," is "socially immature" and "irresponsible." He feels Andy will *never* be responsible because of the disability. But when questioned, Tom admitted that he's given Andy few opportunities to *be* responsible.

And that's the conundrum! If others don't *believe* you can be responsible, you're never given opportunities to be responsible, so it's practically impossible to learn about personal responsibility, then others continue to see you as irresponsible, and the cycle continues. Worse, when an individual expresses a desire to achieve greater personal autonomy, his hope may be pooh-poohed as "unrealistic." If he tenaciously hangs on to this hope, and if he struggles to assume more personal responsibility, those "in charge" may interpret his actions as "non-compliance" or "inappropriate behavior," for which there may be serious and painful consequences. *He can't win!*

The root of this problem is *not* a person's disability, but is, instead, a consequence of *our attitudes and actions.* (It's also the result of social policies, as detailed in the article: "The Disability Business.")

I believed what Sonia told me about the people at the group home being unable to tell time. But I don't agree that this makes people incapable of being responsible for taking medications or making doctor's appointments. Why? Because there are people *without* disabilities who have trouble doing these same things, and they don't have someone taking control of their lives! Instead, they use watches and clocks with alarms, PDAs (personal data assistants), and other devices. I'll bet Sonia doesn't leave the house without her day planner and other helpful tools to make sure she stays on track! Why can't the same be true for people with disabilities, to enable them to be more responsible?

Now let's look at Tom again. When he was growing up several decades ago, he pushed for some personal responsibilities (deciding about clothes, hair, music, etc.), while other responsibilities were *demanded* of him by his parents (coming home on time, being a careful driver, etc.). But as Tom reluctantly admitted, the same has not been true for his son.

Concerned about the behavior aspects of Andy's disability, Tom is fearful Andy will make "wrong" choices, so Andy isn't allowed to make *any* choices. If Andy isn't permitted to do this at home, where he'll still be safe even if the choices are wrong, how will he learn to make good decisions when he's an adult and on his own? He won't! And this may lead Andy's parents to place him in a sheltered, segregated group home, where others will continue to control his life.

When people do not have personal responsibility over their own lives, they cannot lead real lives. They live more like—take your choice—slaves, trained animals, or perpetual infants.

It seems that we prevent people from becoming personally responsible because we believe they're incompetent. And when this occurs, we may do too much, too little, or do the wrong thing altogether.

When we do too much, people learn helplessness. This may begin very early in a person's life when she's a child at home. Parents, brothers and sisters, relatives, teachers, and others do "for" instead of "with." Doing "with" is one way of helping another learn about responsibility, making choices, and more. Allowing a person to experience the "dignity of risk" (making decisions and living with the consequences) is another positive, helpful strategy. And if a person is always in a sheltered, segregated environment (living, working, or at school) in which others are in control, and when strictly-enforced rules and regulations are the norm, his opportunities for autonomy and personal responsibility are severely limited. It's never too early, and it's never too late, to do whatever it takes to help a person become more responsible!

Doing too little often occurs when we don't provide the tools (such as assistive technology devices), supports, accommodations, or environments that allow or encourage decision-making and taking personal responsibility. My own 16-year-old son has difficulty reading a traditional clock/watch. But with his digital watch and clock, he can be responsible for his own schedule.

We often do the wrong thing altogether, like making decisions about a person's life based on the diagnosis, instead of the person as a unique individual who has specific wants, needs, interests, likes, and dislikes. Pigeon-holing people based on their diagnoses should be a relic of the institutional-era, but it's still a common, and horrific, practice in schools, living arrangements, workplaces, and other environments. When we make decisions based on a person's diagnosis, are *we* lazy, ignorant, or both?

Regardless of our roles—family members, educators, service providers, or others—we can examine our own actions to make sure we're not making another person dependent on us. And this is something that must be practiced daily! It's so very easy to slip into patterns of behavior that reinforce "learned helplessness" in others! We must presume competence in others, and do whatever it takes to provide the tools, supports, and environments that enable a person to take more responsibility for his life.

Should we expect a person to be *totally* responsibility for his life? No, because you and I are not totally responsible for our lives. I could not survive, much less be successful, without the help and comfort of family, friends, and others, and without tools, accommodations, and supports. Personal responsibility is not about "total independence"—that's a myth. No one is truly independent; we're all *interdependent* on each other.

In the end it all comes down to this: what would you want if it were you? Do you want to be controlled by others or do you want to take personal responsibility and live life your way? It can really be that simple, if we use our common sense and have respect for others. And sometimes, it can be even simpler: we may just need to get out of the way and let things happen.

Now, let's look at personal responsibility as it relates to parents and families: why and how parents relinquish personal responsibility, how this may affect the child and family, and what the long-term effects may be on the child once he becomes an adult. When parents do not take personal responsibility—when we're not in charge of our own family's life—we don't live real and authentic lives. Instead, we live as clients, recipients, or consumers—and others are in control.

When I do presentations to parents of younger children who have disabilities, I share the "news" about the 70-75 percent unemployment rate of adults with disabilities. Some parents are familiar with this deplorable state of affairs, others aren't. I follow with a question: "Is this the dream for your child—that he grows up to be unemployed, living in a congregate living environment, subsisting below the poverty level, receiving SSI, Medicaid, and possibly food stamps?" As a group, parents vehemently respond, *"No!"*—this is not the dream they have for their children. This might have been the dream for parents several decades ago—parents whose children were incarcerated in institutions: a group home was preferable to an institution. (But we also have to wonder if *that* was the dream of the children.) Conversely, this may *not* have been the dream of many parents (or their children), but somehow, whatever dreams they had evaporated, and their children *did* end up unemployed and dependent on The System. So the message to parents (and anyone else who cares about children with disabilities) is: unless we begin doing things differently right now, many of today's children will most likely maintain the horrifically high unemployment rate when they become adults.

How is all this connected to personal responsibility of parents? From my perspective, from the moment parents enter Disability World (the world of services, rights, entitlements, etc.) at the time of diagnosis, they're at risk of relinquishing personal responsibility of their children/family. Many parents quickly become dependent on therapists, physicians, or other professionals. Some may not be aware of this emerging dependency as it's happening. Others, however, intentionally take this route; allowing—or even demanding—that others take responsibility (and this may be the way they operate in other areas of their lives).

Years ago, the mother of a two-year-old faced a dilemma—one that's not uncommon. She asked, "The pedi-neurologist says one thing, the pedi-ortho doc says another, the therapists say different things, and so does the service coordinator! Who is in charge—which one do I follow?" My response was that *she* was in charge and that she must assume responsibility for thoughtfully considering everything that was recommended (asking for more information, if necessary), and then make the final decision on behalf of her son.

As parents, we often follow the dictates of professionals, thinking *we're* in control and that we've "made a decision," when we're actually just "following orders." We often do not *evaluate* the recommendations to determine if they're right for our child or family, and we may not consider or ask about other options. This might work fine for awhile. (And during this time, we have unknowingly relinquished our personal responsibility.) But at some point, a parent may be uncomfortable with a professional recommendation, and if she hasn't actively made decisions in the past, she may feel unable or unwilling to question professional expertise.

Should you fail to pilot your own ship, don't be surprised at what inappropriate port you find yourself docked.

Tom Robbins

The ways we relinquish responsibility are numerous. When questioned about what their children are learning/doing in a special ed resource room, many respond with, "I'm not sure." They can't recall what was written in their child's IEP (Individualized Education Program) and they seem content to allow their children to spend seven or eight hours a day, five days a week, doing who knows what. I'm not sure whether this represents extreme trustworthiness or extreme carelessness. (Would we allow our children to spend this much time in other settings, not knowing what they're doing? If not, why is it acceptable to do it with a public school?)

Other examples of relinquishing parental responsibility include parents (1) dropping their children off at therapy sessions *or* attending sessions as passive observers instead of active participants; (2) taking little or no interest in writing IEP goals and/or working with the school to ensure the goals are met; (3) letting their children go without assistive technology devices or other supports/accommodations because someone else (The System) won't provide them, instead of seeking out and acquiring these things on their own, using any means possible; (4) turning their young adult children over to the adult service system; and more.

Some parents might want to punch me right now, fuming that they *want* to be more involved in writing IEP goals or other activities on behalf of their children, but they're prevented from doing so by educators or service providers. I know all about this; been there, done that. When my son was very young, I "followed orders" and was labeled a "good mother." But once I began to question and started saying "no" to certain professional recommendations, the label changed to "non-compliant parent." When others attempt to exclude us from responsible participation, we can and should flex our parental responsibility muscles, respectfully and politely, but firmly. We must—our children are counting on us!

Simultaneously, there are many professionals who never *intend* to take over, but some do so by default when parents refuse to assume responsibility. In addition, there are other professionals who work diligently to ensure parents *do* stay in control of their children's lives, but some parents thwart these efforts by insisting that professionals assume more responsibility.

The worst-case scenario, from my perspective, involves parents who quit their jobs or refuse to accept a pay raise so they can maintain an income low enough to quality for SSI, Medicaid, and/or other government benefits for their children. While these may be considered important benefits, they're paltry compared to the salary and benefits of many good jobs. Instead of settling for the government dole, why wouldn't a parent do whatever it takes to secure a job with good health insurance and a decent salary? Is it because dependence is easier? It might be, but what's really best for the child and family?

Relinquishing personal responsibility of our children can have dire effects on us all. As parents, we can end up feeling incompetent, unable, ignorant, angry, sad, and more. These feelings can rub off on everyone in the family, creating unneeded stress and tension. In addition, children who grow up in families where personal responsibility has been relinquished are at risk of becoming adults who have little or no sense of personal responsibility. They've learned the lessons of their parents well.

> Give a man a fish, feed him for a day.
> Teach a man to fish, feed him for a lifetime.
> Wisdom of the Ages

As adults, they're thought to be incompetent and are then at the mercy of The System. They may have no clue how to (1) continue their education after public school or acquire a real job, (2) live on their own (with a roommate for support or other accommodations), or (3) handle the day-to-day activities of real life, such as speaking up for themselves, having relationships and romance, paying bills, and all the other characteristics of adulthood. Many of today's adults with disabilities receive training to address these needs. Classes in sexuality, cooking, and other topics may be available to some. For others, service providers write goals to address their "problems."

Why, though, didn't they learn these things as children from their parents and from the natural experiences of childhood, the way their brothers and sisters learned? My hope is that today's parents can learn from the experiences of the past so their children will learn about personal responsibility *as they grow,* and the need for classes about "adult living" and/or goals to address those needs *will no longer be necessary.* This change can occur if our children learn from us as we take personal responsibility, and if we, as parents, cede this responsibility to our children as they grow. To that end, following are some suggestions that may help create a strong foundation:

—Thoughtfully consider the services, treatments, and all other interventions that are offered: ask questions, consider alternatives, seek other opinions, and discuss all options with your entire family, including the child with a disability—it's his life! Do whatever it takes to make sure you're actually making a decision, instead of acquiescing to conventional wisdom. *We don't have to be sheep!*

—Ensure children with disabilities experience the same opportunities for personal responsibility as their brothers and sisters, such as having assigned chores, helping around the house, receiving an allowance, and so forth. If a child's condition prevents him from doing things in the same way as other children, modify the task or provide accommodations to make sure the child enjoys the accomplishments, achievements, and self-respect that come with personal responsibility.

—Do what it takes to ensure a child participates in decisions about his life, from the earliest moment possible. A two- or three-year-old can and should have a say about therapies and other services; a school-aged child should be involved in the IEP process, writing goals, accommodations and supports, and curriculum modifications, etc.; a teenager should be expected to get a part-time job (and helped to do this, when necessary); and so forth.

The familiar platitude, "Children learn what they live," is appropriate to this issue. From our actions—whether we're parents, educators, service providers, or anything else—children will learn responsibility and self-respect so they can enjoy the lives of their dreams. Or, they can learn how to abdicate personal responsibility and allow others to control their lives—lives not of their choosing. Consider this wisdom from William James, the great American philosopher and psychologist: "When you have to make a choice and don't make it, that in itself is a choice."

For too long, the presence of a disability has been used to exempt individuals from personal responsibility. Isn't it time to stop robbing people of opportunities, the freedom to choose, and the self-direction and pride that come from personal responsibility?