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# The Truth Comes From Us: Supporting Workers with Developmental Disabilities

Max Barrows

Jason Billehus

John Britton

Allison Cohen Hall

University of Massachusetts Boston, [allison.hall@umb.edu](mailto:allison.hall@umb.edu)

Juliana Huereña

*See next page for additional authors*

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**Authors**

Max Barrows, Jason Billehus, John Britton, Allison Cohen Hall, Juliana Huereña, Nicole LeBlanc, Eric McVay, Karen Topper, and ThinkWork! at the Institute for Community Inclusion at UMass Boston

# The Truth Comes From Us

## Supporting Workers with Developmental Disabilities

*By Max Barrows, Jason Billehus, John Britton, Allison Cohen Hall, Juliana Huereña, Nicole LeBlanc, Eric McVay, and Karen Topper*



**Employment professionals play a powerful role in the pursuit of true inclusion. This paper by self-advocates outlines key steps on how allies can move people with developmental disabilities out of poverty and into the heart of our communities.**



# ThinkWork!

## On Target by John Britton

In 2000, I was living on my own with really supportive personal assistants coming in the mornings and evenings. But I just lost my job that a high school teacher had helped me get at an attorney's office. What to do next? I shopped at Target all the time. I like to help people and thought it would be a good place to work. My parents were worried and said, "Johnny, I don't know about this one."

Back in those days you asked for an application. The person I asked said, "Who is this for?" I replied, "It's for me." They responded with a puzzled look saying, "Really?" I said, "Yes," and rolled away.

My assistant helped me fill out the application. I turned it in the next day. The person said, "Thank you, we will call you." I called them after a few days. It took a couple of times for them to figure out what I was saying. I would say, "Wait, don't hang up, I want a job." They kept saying the person who hires is not here. I kept asking and got a time to see her.

I went in to see her and she said, "We don't have anything right now." I kept on bugging them. When it rained I called. When the weather was nice, I would roll in and ask to see her. If she was busy I would tell them I would shop and wait for her. Then she would say, "Hi John, wow you don't stop." I went in about five times over a month. They figured I was not kidding around. They eventually called me for an interview.

I was so excited for the interview. I went with a personal assistant. Like many times in my life, I introduced my assistant saying, "She is here to interpret if you don't understand me. But please, talk to me, not her." She sat in on the interview, but only interpreted when she needed to.



The Target manager seemed ok with it. She asked me, "What can you do for us?" I answered, "I really like Target and want to work here. Let me look around and see what I can do and come back to you." We parted positively and with a smile.

Over the next couple of days, I looked around the whole store. When I met with the manager again I said, "I have been looking around and it seems like you need some help keeping the service desk returns picked up. I can put stuff back." She replied, "Oh, you're right. The 'go-backs' area does get busy and extra help is always needed. Anything else you're thinking about?" I suggested, "What about if I keep things picked up around the store?" I added, "Give me a chance and if I don't do a good job I will roll out of here."

The rest is history. I have been working at Target for 16 years now. That includes a move from Illinois to Arizona, where I transferred stores but stayed with the company!

The lessons for employment professionals are: help when asked, and assume I can do it on my own unless I ask for help. I can do my job mostly without supports. I get some help at break time—to eat lunch or to shop. For the most part, when I need help, I'll just ask a co-worker.

## INTRODUCTION

Inclusion is a birthright and work is a human right. Every American has the right to work in their community without any kind of discrimination. People with disabilities can work and handle a job. We know what we are doing. We know how to speak up and speak out for ourselves.

US law says service providers need to believe that people with disabilities can work. The Rehabilitation Act says people can work regardless of the severity of their disability, if the right services and supports are provided.

### Why do we want to work?

- Having a job builds confidence. People see what we have to offer.
- Working allows us to give to the community and to not just be seen as taking.
- When we make our own money, we can take care of ourselves. Life takes money. When we make money, we are in charge, and no one can tell us how to spend it.

### What's important for employment professionals to know?

We want employment professionals who see us as real people, without judgment. They have a lot of power. They can provide support in a way that makes us feel strong and proud. OR, they can do it in a way that makes us feel worthless, and less than the people we really are. Our suggestions describe ways to tap into the strength and support of employment professionals

## ABOUT SABE AND OUR SOURCES

Self-Advocates Becoming Empowered (SABE) is a self-advocacy organization. Founded in 1990, we have been working hard for the full inclusion of people with developmental disabilities in our communities throughout the 50 states for 26 years. Our non-profit advocacy organization is run by a board of 16 people with intellectual and developmental disabilities representing nine regions of the country.

Information for this paper was gathered by a team of four SABE board members and three people from state self-advocacy organizations. We reviewed policy statements and presentations written by SABE members during the past five years. We also talked to:

- current and former SABE board members from all regions of the United States;
- peer leaders representing the New England states and New York during a regional meeting in May 2015;
- at least 45 self-advocates from all over Vermont during a statewide meeting in June 2015.

People with intellectual and developmental disabilities shared their perspectives based on their personal experience receiving support to work. Once the SABE team reviewed the information, we identified several themes from what self-advocates shared.



and use it to empower people with disabilities to be all we can be.

“I want to let the lookers know that I’m a real person in this body. I know the world is full of judgment. But also the world is big on knowledge. Use the knowledge to stop the judgments. Let’s unite to challenge narrow-minded people, full of judgments.”

–KYLE MORIARTY

“People should never be looked upon as empty spaces. Presuming that one is not intelligent, just because of outward appearances, is a tragedy. Judging one’s understanding by their form of communication or ability to socialize is deadly.”

–KRIS MEDINA

## THEMES

### 1. Get to know me.

- Be good at assessing my skills.
- Listen to me.
- Always be respectful with actions and words.
- Have high expectations—motivate and encourage me.
- Ask me how you should introduce yourself to others. For example, “I am Joe’s support person, his ally, or his employment professional...”
- Look beyond manual labor when

you are helping me find a job. Seek out all types of careers, including public speaking and government jobs. Push for people to be employed as professionals at developmental disabilities service agencies.

- Know my goals and dreams, especially relating to getting the perfect job!

“You need to know me and how my disability works.”

–JASON BILLEHUS

### 2. Teach me to do my job.

- Know how to step up (assisting me when I get stuck) and step back (letting me be independent).
- Help me build natural supports through supporting me to get to know my co-workers.
- Pay attention to how fast the job needs to be done and match it to what I can do.
- Support me to learn “soft skills.” For example, help me share with my boss and co-workers the best ways to communicate with me.
- Include me when talking or emailing about me with my boss.
- I don’t mind if you tell me how to correct a mistake, but do it in private.
- Support me to learn to stay safe when I am working.



"The most important thing ever is to be successful on my job. Make sure I am doing my job right. But whisper it or write a note. In other words, do it in private so I am not embarrassed."

—SABE MEMBER

### 3. Help keep me balanced so my emotions do not interfere with my work performance.

- Be aware of stressful situations.
- Know how to take the pressure off of me.
- Support me to get along with others.
- Support me to know what to do if I feel overloaded.



"After a busy day at work and being around people, my brain needs a moment to release energy that builds during the day. I call it an energy release, shaking the energy out of me. I need a break from the real world, into my own world. Some people might call that a 'meltdown,' which is a judgmental description. I call it an 'emotional energy release,' which I feel is a non-judgmental description."

—MAX BARROWS

### 4. Make adjustments to the job site for ongoing success.

- Take a close look at what I do and make sure I have the right tools for the job.

- Support me to organize my job space to keep it simple, and so that I can reach everything I need.



- Be aware of how I can use technology to make my job easier.
- Identify what types of devices and software could be used to increase my independence.
- Make sure the environment is sensory friendly. For example, if the lights are too bright, see if I can move to a space with lower lighting.

"Thanks for the assistance, but remember it's my job not your job."

—STIRLING PEEBLES

### 5. Be a good role model!

- Keep it positive—focus on my strengths and interests.
- Be organized and act with a professional attitude. For example, be on time, avoid using your cell phone when we're together, and let me know if you have to leave.
- Presume competence. When you meet a person with a disability, assume they are capable.
- Be flexible, because our work schedules may change.



“Unfortunately many people with disabilities grow up in the shadows of ‘Low Expectation Syndrome.’ Our hopes and dreams can be stripped away by doctors, teachers, parents, and providers who have preconceived notions about what we are capable of doing.”

–NICOLE LEBLANC

## 6. Recognize the importance of peer-to-peer connections.

- Support me to connect with peers as an additional source of information on employment and life in general.
- Be aware that problem solving with a peer can give me new ideas that fit my way of doing things.



“Our peers have been out in the workforce as a person with a disability. We want the truth from them. Sometimes employment professionals ‘sugar-coat’ the information. Peers are better at knowing how to deal with discrimination and problems of people not accepting us for who we are.”

–RANDY LIZOTTE

## 7. Know we may run into ongoing barriers, and keep supporting me!

- Support me to figure out reliable transportation.
- Support me to learn about and deal with discrimination on the job.

“You need to keep people in jobs, not just find them. You need to be there for folks who lose their jobs and help them find another job.”

–SABE MEMBER



## CONCLUSION

If employment professionals follow our recommendations, we can all hope and expect to see more people with developmental disabilities in the workforce. The themes identified in this paper should be incorporated into trainings for employment professionals.

As employment professionals receive more education, they will be in a better position to empower the people they support to pursue their dream careers. We need to move away from the tendency to place people in manual labor jobs, and make sure that we consider jobs based on people's strengths and interests.

Imagine a future in which all individuals, including those with significant disabilities, can aspire to follow their dreams and become professionals. With the proper support systems in place, for both people with developmental disabilities and employment support professionals, this future is entirely possible.

Eventually, our goal is to double the overall hours worked by people with developmental disabilities, and employment professionals can help make that a reality. It is our hope that with adequate support, education, and positivity, everybody will be able to fulfill their potential. Our take-home message for people reading this paper is to presume competence and have high expectations for all people with intellectual and developmental disabilities.



The Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities. The contents of this brief were developed by our partners at Self Advocates Becoming Empowered (SABE) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR Grant # 90RT5028-01-00). NIDILRR is a Center within the Administration for Community Living (ACL),

**For more information:** Allison Hall | [allison.hall@umb.edu](mailto:allison.hall@umb.edu) | Institute for Community Inclusion

[www.ThinkWork.org](http://www.ThinkWork.org)