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Right Science and Right Results: Lifestyle Change, PBS, and Human Dignity

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Abstract

This article provides an in-depth analysis of the comprehensive supports necessary for an adult with multiple disabilities and significant problem behavior to experience an inclusive adulthood. Written from the perspective of parents, the article highlights "lessons learned" about how to implement and finance comprehensive supports across domains of home living, work, friendships, community connections, wellness, as well as additional areas. Practice tips are provided in terms of potential replication.

Keywords

PBS, lifestyle change, significant disability, adulthood

Our son Jay Turnbull died wholly unexpectedly and instantly on January 7, 2009, struck down by a massive heart attack. He was 41½ years old. Here, as a guide to researchers, practitioners, families, and policy makers, we seek to connect his life to the ethically right science that PBS represents, the art of implementing the science, and the ethically right result of that science, namely, Jay's life of great dignity.

In one of the seminal articles about PBS, Horner and his colleagues (1990) identified and described nine features of the then-emerging PBS technology. One was lifestyle change:

> The positive/nonaversive approach focuses on the lifestyle of the individual. . . . Behavioral support should result in durable, generalized changes in the way an individual behaves, and these changes should affect the individual's access to community settings, to social contact, and to a greater array of preferred events. . . . An effective behavioral support plan should integrate procedures for building access to activities, places, people, and events in addition to modifying the patterns of specific desirable and undesirable behaviors. (Horner et al., 1990, p. 127)

We responded to the "lifestyle" article by describing two stages in Jay's life (A. P. Turnbull & Turnbull, 1990). In the first stage, while he was in a community service system (a congregate care "setting" or "environment" consisting of a group home and sheltered workshop) for less than a year, he was segregated and subjected to aversive interventions. In the second stage, while he lived in his own home (a much different "setting" or "environment"), he had significant control over his life and he experienced inclusion and PBS. Reflecting on the two stages, we argued that a PBS-driven lifestyle required us to (a) develop daily and weekly schedules for living, working, recreating, and socializing; (b) locate control of the person's life in the person, family, and their chosen advocates; and (c) ensure that professionals collaborate with them in carrying out their preferences. We stated that PBS should not be conceptualized as being superimposed on one's living condition but rather it should permeate all aspects of a custom-designed lifestyle characterized by personal control, independence, integration, and productivity (A. P. Turnbull & Turnbull, 1990).

When Jay died, his behaviors were rarely challenging; their frequency and intensity had abated; his mood swings had stabilized. He had scads of friends. He had events and people to anticipate. He was fully engaged in his home, work, and community. He delighted in music and others shared his delight. Diagnostically, he had not changed. He still had the same IQ in the "severe" range, but his JQ (joy quotient—the degree to which he enjoyed life and because of which he had fewer difficult behaviors) was at the genius level. His medication was finally calibrated to modulate his bipolar condition, after years of trial and error. We had combined the science of PBS with the science of pharmacology, and

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we had added "art"—the individualized implementation of both sciences and the provisions of supports that were driven by Jay's choice as well as his needs. He now was the "true" Jay—a person loved and respected by all who knew or knew about him, a man with boundless enjoyment of his life.

How did such quality of life, such congruence with the ethical principle of dignity, such consistency with the constitutional principles of liberty and equality occur? How did Jay's life become so enviable? The answers lie in three foundations for his life, his weekly schedule of comprehensive supports, and four elements of a dignified lifestyle.

Because this is a brief article revisiting our 1990 article about Jay and describing his life as it was at the beginning of 2009, we do not provide data to the degree an author would if describing a particular intervention carried out over a much shorter period of time than those many years. We, however, want to assure the readers that we have used PBS in its scientific way, namely, by relying on data.

We have documents replete with data related to Jay's behavior. They track his life from birth to death. The data about PBS, however, deal primarily with the last 20 years of his life, 1989 to 2009. We discuss only one of the two data-collection processes and forms in this article and incorporate a figure displaying one of the forms. The recording was by individuals having daily contact with Jay and was supervised (and the data-takers trained) by two PhD PBS specialists.

The number of person-hours spent in data-collection, analysis, and response to analysis was as few as one a day or as many as six a day. It is reasonable to conclude that the "science" we applied required literally thousands of person-hours in those 20 years.

This article, however, is not the one for telling about the data protocols we followed. Instead, this article is about a life of quality as a result of science, the art of living, and support to live well. Right science and right results are our focus, with less emphasis on the science than on a man's life. We were scientific; we were artful, too; and, most importantly, Jay experienced a magnificent quality of life.

Three Foundational Components

The three foundations for Jay's quality of life included following his leads, identifying and merging funding streams, and having a home of his own with caring housemates.

Following Jay's Lead

Jay was our best professor, but he almost always gave us our final exam before giving us the full course. He challenged us, guided us, and catalyzed our learning. Despite having coexisting autism, intellectual disability, and a bipolar disorder, he instinctively knew that he deserved valued relationships. He also was so strong-willed that he must have known—not in a full-fledged cognitive sense but in other ways—that being in control of his life, not ceding it to others, was the only route to the life he wanted. Jay sent a single sun-hot message: He would and could change only if we ourselves would and could change.

Ironically, too, Jay had greater expectations for his life than we did as he entered his young adulthood. We were exhausted from years of advocating for him and balancing his interests with the legitimate ones of his younger sisters. Recognizing that there was one and only one adult-service system in our community, we accepted what was available, knowing, in our hearts, that we were compromising Jay and ourselves. One of us served on the agency's Board of Directors, and both of us believed that we could become partners with agency leaders and propel the agency toward more inclusive and evidence-based services.

Jay was the first to quit that system, telling us by his behavior that he was through with it. We followed in short order, withdrawing Jay a nanosecond before the agency staff announced they were expelling him.

There is an irony in the failures of those days and in Jay's role as our best teacher. It is that every year thereafter we learned more and more about how to secure Jay's choices and his dignity. Choice became more than a core concept of disability policy (H. R. Turnbull, Beegle, & Stowe, 2001); it became a necessity in our and Jay's life. And dignity became more than an ethical aspiration (H. R. Turnbull et al., 2001). It became the outcome of our response to Jay's choices.

After leaving the agency, we were wholly alone: no other adult system existed in our community. To provide a decent life for Jay was one that did not have to exist if the agency had shared Jay's and our visions and had the will, skill, as well as administrative structures to individualize for him.

We were now operating solo, without any agency support. We regret the time we spent, after leaving the agency, in doing the job that agencies were created to do; we would have preferred to spend our "Jay-time" with Jay in more pleasurable activities. Families should not have to, or be expected to, build and orchestrate such complex lifestyle support on their own.

Did Jay's several disabilities create the ultimate challenge for us? No doubt, they were challenging. But they were not the root cause of the ultimate challenge we faced.

He had an instinct toward dignity, a biological drive toward autonomy. All we could do is follow him. And as we did, his behaviors—self-injury, property destruction, aggression, and running away—receded. When life—we or agencies—challenged him, he challenged it right back. When we sought to change him, he taught us to change ourselves and to change systems. When his world was not as he wanted it, then the people in his world had to change it. He demanded more from us than we did from him. Approaching his behaviors from a PBS stance was necessary, but only when we recognized that we and the adult system were the challengers and that he was not the challenger did we begin to "get it right."

Identifying and Merging Funding Streams

One factor that allowed us to respond to Jay's choices and to assure his dignity was his access to Medicaid's Home and Community Based Services (HCBS) waiver program and, within it, the option for participant direction (PD). The HCBS program permits states to use federal Medicaid funds, supplemented by state funds, to support income-eligible individuals with significant disabilities in the community, not in institutions.

When Jay was enrolled in the adult service system, the agency operating the system received his HCBS benefit and provided him with group home and sheltered workshop programs within which he had no control. Indeed, the agency was not at all atypical; its mode of doing business was the norm in the late 1980s. We knew then and must emphasize even now: Tradition and goodwill are no substitutes for good science and valued outcomes; each is necessary but neither alone is sufficient.

Change came when the Robert Woods Johnson Foundation (RWFJ) launched its Systems Change Project. Under it, a participating state, including Kansas, had the option to allow HCBS beneficiaries control over the Medicaid funds (budget control) and over the staff paid by those funds (employer control). Because Jay had very effective means of expressing his choices through his behavior, he guided us and his reliable allies in orchestrating a lifestyle to suit his choices, supported by self-directed Medicaid funding.

HCBS was not the only source of financial support for Jay's chosen, dignified life. He received SSI before Rud, his father, took his Social Security Retirement benefit in 2002; he received SSDI thereafter. He worked 20 hours each week at more than the minimum wage, benefiting from supported employment training through the state vocational rehabilitation program. He also received a Section 8 Housing voucher.

In short, once we understood and then marshaled all of the public support available to Jay, choice and dignity followed. Rights run with revenues, and choice and control are the consequences of cash.

Having a Home of His Own and Caring Housemates

After Jay left the service system, we hired a young man, Chuck Rhodes, to take Jay to exercise at a health club one day a week. Chuck was the educational advisor at a Kansas University fraternity, Sigma Alpha Epsilon, and often took Jay to the fraternity house after they exercised. There, Jay met and was befriended by Pat Hughes and Cory Royer. Pat and Cory first connected with Jay through music (Jay's gift), and within a short period of time the fraternity had voted to make Jay an "honorary brother."

Soon, Pat and Cory suggested that Jay move out of our home into his own place so that he could establish a life of his own in the community. They also said they wanted to be his housemates. With assistance from trustees of a trust created for Jay's benefit and with an equal amount of our own funds, we purchased a home for Jay in 1990 and arranged for Pat and Corey to live there free (no rent or utility charges). They "paid rent" through their work with Jay—"sweat equity," supporting Jay Monday-Friday. To satisfy Jay's desire to continue to be part of our family (especially to ensure that his sisters, Amy and Kate, would have regular contact with him) and to give respite to Pat and Cory, Jay returned to our home every weekend.

Pat and Cory launched Jay into having a home of his own. Predictably, they—as young men—had their own dreams to pursue, and they left but remained as Jay's friends. After they left, Shahla and Jesus Rosales became Jay's housemates. They were PhD students in applied behavior analysis and exquisite therapists and beloved friends. The next set of housemates were lively music therapists. Each of Jay's many subsequent housemates—Tom Allison, Elizabeth Giffin, and Lillie Cusic—had special gifts to offer, including sophisticated behavioral training. We never had to advertise to hire anyone. We always provided each with a great deal of information about Jay, with advice on how to support him and partner with us, and how to document what they are doing for and with Jay.

Now, Jay lived in the world he wanted: he had the passionate commitment of people who brought predictability and stability to his life and who wanted and were able to respond to his choices. He and they delighted in hosting parties, bringing laughter to his home, and creating a circle of support around him.

During the 10 years beginning in 1990 and ending in 2000, his housemates invariably were students at the University of Kansas. When they graduated, they left Jay and us but not until, on their own, they recruited other housemates for Jay. This self-regenerating system of support rarely required us to do more than approve the new housemates and, in partnership with the outgoing veterans, tell the rookies how Jay wanted to live and how to respond to his choices. Jay's housemates did the daily joy-quotient living, and we were the orchestrators of the process, attending to the overall logistics, finances, and supervision.

The rotation-system changed in 2000 when Jay enrolled in the RWJ Foundation Self-Determination/Participant-Direction Program. Having control of all of Jay's HCBS funds, having marshaled other Social Security and housing benefits, and having combined them with Jay's earnings, we now were able to take choice and lifestyle to a still higher level. We could spend the HCBS and other Social Security funds (SSDI) to hire housemates and other members of a support team. Sweat equity gave way to publicly funded participant direction.

From 1990 through 1994, Jay's housemates were Anne Guthrie and her partner Richard Gaeta. Like other housemates, they followed Jay's lead but gave value-added support: Both were exceptionally social, Richard the Italian chef, Anne the hostess with the mostest. Jay's home and life had an abundance of joviality.

Jay's final housemates were members of the Riffel family—Laura, Tom, and Bryan. Laura and Tom were Jay's housemates for almost two years. Their son Bryan took on that role for an additional three years when Laura and Tom moved out of state. Tom and Laura later returned and lived with Jay for another 4 years, until he died. As a PBS specialist, Laura brought the science to Jay's life, morphing into an ideal combination of Mary Poppins and a Marine Sergeant Major to support Jay in his choices but to prepare him to assume his responsibilities at home and work.

Tom, new to disability work, had the full-time job of supporting Jay so he devoted his sole attention to doing just that. Tom quickly learned Jay's quirks and played on them to support Jay to be responsible—to get out of bed even when depression locked him in, to calm down even when mania riled him, to communicate with words and not behaviors, and to play games that bound the two of them together.

Tom also learned that he and Jay needed a break from each other, so Tom brought in his other son, Brandon, who then brought in his girlfriend, Sarah Johnson, and his high-school buddy, Bobby Young, who brought in his sister, Andrea, and so on. The system that had worked to secure housemates now worked to secure people who, together with music, speech, and massage therapists and a yoga instructor, energized Jay and brought him joy.

Inarguably, Jay was living the kind of life Horner and colleagues had described; it was the life he wanted. As important as that fact is—it describes the consequences of the system we just reported—equally important is the single means by which Jay obtained that enviable life. That means, that key, is the genuine connection—dignity, not pity or compassion—that pervaded Jay's home. Self-selection—good people bring in only other good people—works when those people respect Jay and feel a bond with him. As Jay often reminded us, he lived in a "home," not a "house." He understood the distinction: The former is a place where dignity abounds; the latter is a structure into which dignity can be added but often is not.

Weekly Schedule of Comprehensive Supports

Like many people with and without disabilities, Jay needed regularity in his life, as well as variety. As we explain more fully below, he needed the regularity of routine and people; but he needed many different people and for them sometimes to vary their usual activities. Overall regularity, and variety within the regular schedule, were the "rules of engagement"—the rules that kept Jay engaged with others and in his life. When he had both, he was a content and happy man; when he lacked either or both, he found life challenging and, in turn, his behaviors became challenging. As Horner et al. (1990) noted, access to preferred activities is one element of PBS; the other is behavioral change. The two are codependent, as Jay taught us when he left the adult system.

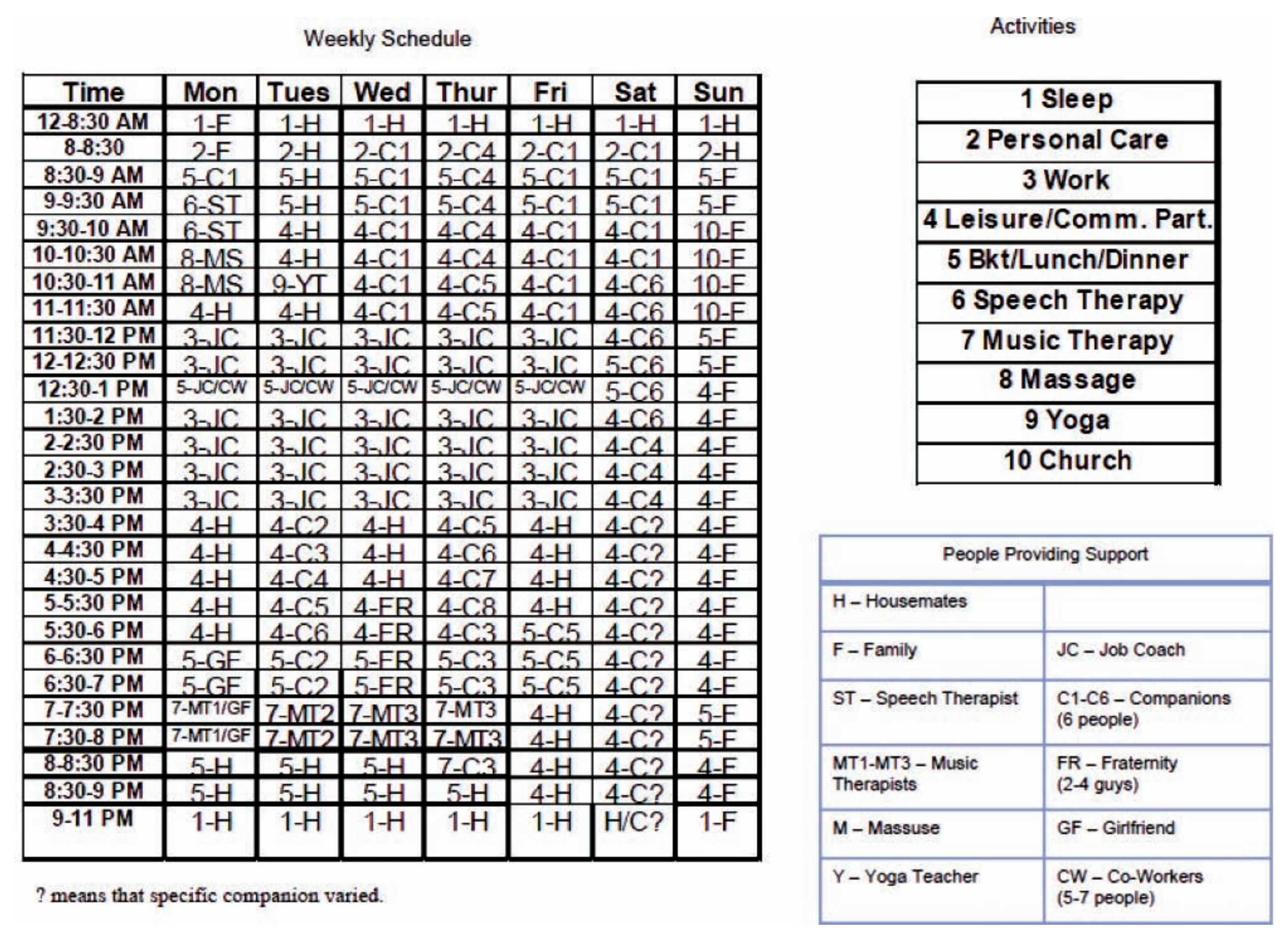
Having learned that lesson and with the constant and creative insight and partnership that his housemates provided, all of us in Jay's life developed a weekly schedule that combined predictability with variety, all grounded on Jay's choices. During the years since leaving the traditional service system, Jay's "support team" included ourselves and his sisters and brother-in-law, his extended family (most recently, the Riffels and their kin and connections), and many loyal allies (especially Amy McCart and Nina Zuna of the Beach Center, Jane Wegner at the KU speech-language clinic, and Alice Ann Darrow, the professor in the KU music therapy program but now at Florida State University). Figure 1 displays a typical week in his life during the past decade.

Regular Activities

Jay's week was typical for almost any person, irrespective of disability: sleep, meals, personal care, work, and leisure/community participation. These, however, are necessary but not sufficient as the basis for a PBS-shaped life, for a life reflective of Jay's choices, and for a life in which prevention and wellness, not intensive intervention after a behavioral "incident" occurs, constitute the norm. Accordingly, Jay had four types of regular therapy—speech, music, massage, and yoga. Sunday worship provided another weekly opportunity for Jay to engage in ceremonies—a standard liturgy his special handshake (an adaptation of the Sigma Alpha Epsilon secret handshake) and the "peace" handshake to the pastor and "regulars" among the ushers and congregants in nearby pews—that brought him a sense of connection and enjoyment.

Jay was a creature of habit in many ways and thrived on the regularity of his schedule, including the people who provided support. Although he was not able to read, he easily memorized his schedule and enjoyed talking about it when he first woke up as an incentive to get out of bed, enthusiastic for what lay ahead. Remarkably, 22 to 25 different individuals were involved with Jay each week. Each had a regular "niche" in Jay's life. Because of their dependability and irregularity, Jay developed a sense of confidence and Jay knew that he could count on them to not only be present physically but also to connect with him emotionally.

This kind of connection—this deep and regular involvement in each other's life—was especially important, given Jay's autism and bipolar cycle and the wide swings that often occurred, sometimes several times each day, in his



Weekly Schedule

Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
12-8:30 AM	1-F	1-H	1-H	1-H	1-H	1-H	1-H
8-8:30	2-F	2-H	2-C1	2-C4	2-C1	2-C1	2-H
8:30-9 AM	5-C1	5-H	5-C1	5-C4	5-C1	5-C1	5-F
9-9:30 AM	6-ST	5-H	5-C1	5-C4	5-C1	5-C1	5-F
9:30-10 AM	6-ST	4-H	4-C1	4-C4	4-C1	4-C1	10-F
10-10:30 AM	8-MS	4-H	4-C1	4-C4	4-C1	4-C1	10-F
10:30-11 AM	8-MS	9-YT	4-C1	4-C5	4-C1	4-C6	10-F
11-11:30 AM	4-H	4-H	4-C1	4-C5	4-C1	4-C6	10-F
11:30-12 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C6	5-F
12-12:30 PM	3-JC	3-JC	3-JC	3-JC	3-JC	5-C6	5-F
12:30-1 PM	5-JC/CW	5-JC/CW	5-JC/CW	5-JC/CW	5-JC/CW	5-C6	4-F
1:30-2 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C6	4-F
2-2:30 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C4	4-F
2:30-3 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C4	4-F
3-3:30 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C4	4-F
3:30-4 PM	4-H	4-C2	4-H	4-C5	4-H	4-C?	4-F
4-4:30 PM	4-H	4-C3	4-H	4-C6	4-H	4-C?	4-F
4:30-5 PM	4-H	4-C4	4-H	4-C7	4-H	4-C?	4-F
5-5:30 PM	4-H	4-C5	4-FR	4-C8	4-H	4-C?	4-F
5:30-6 PM	4-H	4-C6	4-FR	4-C3	5-C5	4-C?	4-F
6-6:30 PM	5-GF	5-C2	5-FR	5-C3	5-C5	4-C?	4-F
6:30-7 PM	5-GF	5-C2	5-FR	5-C3	5-C5	4-C?	4-F
7-7:30 PM	7-MT1/GF	7-MT2	7-MT3	7-MT3	4-H	4-C?	5-F
7:30-8 PM	7-MT1/GF	7-MT2	7-MT3	7-MT3	4-H	4-C?	5-F
8-8:30 PM	5-H	5-H	5-H	7-C3	4-H	4-C?	4-F
8:30-9 PM	5-H	5-H	5-H	5-H	4-H	4-C?	4-F
9-11 PM	1-H	1-H	1-H	1-H	1-H	H/C?	1-F

? means that specific companion varied.

Activities

1 Sleep
2 Personal Care
3 Work
4 Leisure/Comm. Part.
5 Bkt/Lunch/Dinner
6 Speech Therapy
7 Music Therapy
8 Massage
9 Yoga
10 Church

People Providing Support	
H – Housemates	
F – Family	JC – Job Coach
ST – Speech Therapist	C1-C6 – Companions (6 people)
MT1-MT3 – Music Therapists	FR – Fraternity (2-4 guys)
M – Massuse	GF – Girlfriend
Y – Yoga Teacher	CW – Co-Workers (5-7 people)

Figure 1. JT's weekly supports

moods. He required support that would respond to him as he needed it and when he needed it; the nature of the support was, in part, the use of PBS, as Laura and Tom taught it to those who came into Jay's life.

But the nature of the support was far more than a scientific intervention: Jay knew that everyone with him would stay with him through his challenging times. He knew it because none of them abandoned him—quit their jobs and walked out of his life—after he had challenging times. He knew he had people who deeply cared for him, and this knowledge, this ability to rely on those constantly in his life, was the "art" that we brought to Jay's life, the "art" of PBS. Science alone is necessary but not sufficient; the "art" of living, the permanent presence of reliable allies, is just as necessary and makes the science all the more effective.

Varied Schedule

Predictability can become boring—even for people who experience autism—but variety impedes boredom; Jay's reliable allies built variety into his life. He spent many hours in community activities, supported by many different individuals (see Figure 1). Jay thrived from that variety and his friends (we prefer those words to "support team" because, in fact, the people who supported him were his friends) avoided burnout. He had lunch with different coworkers on a daily basis and had three different music therapists rather than just one.

Jay also had variety in his activities and their settings. He and his friends ran errands for himself and Tom and Laura, and sometimes for us, visiting different stores. They ate at different restaurants. Jay hung out in the apartments of the young people who were his friends, and he enjoyed meals at their parents' nearby homes. Deliberate variety in people and activities enriched Jay's life, but there was constancy below the variety: The people who supported Jay generally did so in a regular schedule. The activities varied, but not so widely that Jay was always a stranger in stores and restaurants—instead, he was a regular and therefore a welcomed customer and patron.

Formal Behavioral Support

Given the comprehensiveness of preferred activities, valued relationships, and the calibration of regular and varied schedules, we found that it was necessary to use more formal PBS procedures during Jay's employment and at home. This work-based support primarily addressed his bipolar cycles, which created greater challenges than his intellectual disability and autism. In partnership with Amy McCart and Laura Riffel, we developed a data chart that enabled Jay's job coach to calibrate the intensity and nature of support at work according to his mood cycle. Although Jay's housemates recorded data when Jay was not at work, they did so in part to inform Jay's job coach about the type of day that he might have. Jay's work day was more structured than the rest of his day. He had responsibilities; other people depended on him. We used PBS to address his productivity in light of his cyclical moods.

In partnership with Jay's reliable allies, we also developed a crisis plan that enabled his job coach, coworkers, and housemates to have a protocol to follow during crises situations. Jay's most intense challenge was staying in bed for several days and refusing to eat, drink, or take his medication. We were helped by Laura Riffel, Amy McCart, Nina Zuna, and Jane Gnojek to get through the crises, learn from them, and increase our capacity to prevent a similar situation in the future. Jay's crises invariably occurred during a "pile-up" time when there was simultaneous occurrence of major setting events such as job coach changes, stressful anticipation of holidays, the two of us traveling too frequently from Jay's perspective, and others around Jay being sick or under stress in their own lives.

Four Elements of a Dignified Lifestyle

The implementation of the weekly schedule of comprehensive supports depended on four key elements: reciprocal relationships, anticipation, engagement, and music (Table 1).

Reciprocal Relationships

Jay had an amazing ability to endear himself to people. He was kind, complimented people, gave them his special handshake, and had an uncanny ability to remember lyrics and a sufficiently joyful voice that off-key singing was irrelevant to the uplift that came through music. He reached out to others, inviting them into his life; he wanted and expected to be loved, for he was unaware of his "difference," oblivious of his limitations.

There is a single point to this narrative: Jay's self-regard shaped the way others regarded him. To himself, he was just "Jay," not a person with a disability who needs intensive and pervasive supports. To many others, he also was just "Jay,"

Table 1. Lessons Learned About Jay's Weekly Supports

- Home of his own
  - Obtain Section 8 Housing voucher
  - Consider floor plan that enables private space
  - Furnish in light of his preferences
  - Consider access to public transportation
  - Consider access to other preferred environments
- Housemates
  - Use Medicaid to pay housemates and provide free rent
  - Have stable housemates who live at Jay's home
  - Have a primary housemate serve as support broker
  - Select housemates who have positive and even temperaments
  - Have housemates model a "sense of connection" for others who provide support
  - Provide breaks and back-up support for housemates
- Personal care and breakfast
  - Arrange work hours later in the day (Jay was not a "morning person")
  - Infuse positive energy into his wake-up routine by conversing about favorite activities in his day's schedule
  - Offer choices about what he will eat for breakfast
  - Respond to Jay's preference about how he likes to be awakened in the morning
  - Vary the morning companion, creating variety within predictability
- Speech therapy
  - Use Medicaid to pay for speech therapy
  - Promote Jay's ability to communicate as a means for enhancing valued relationships, using face-to-face conversation, e-mail, and telephone calls
  - Address Jay's and our family's priorities for communication
- Work
  - Obtain payment for as much job coaching as possible from Vocational Rehabilitation
  - Develop a PASS Plan to save money for employment-related expenses such as a computer or job coach
  - Identify new tasks, teach new skills, and continually enhance competence
  - Calibrate nature and intensity of job coaching to bipolar cycle
  - Distinguish between depression and noncompliance; provide support for depression and consequences for noncompliance
  - Give cash every day as immediate reinforcer
  - Facilitate connections to and conversations with coworkers
  - Have a structured routine of tasks
  - Use preferred tasks on difficult days
- Massage and yoga
  - Pay for these services with SSDI or Medicaid
  - Foster a bond of connection with masseuse and yoga teacher
  - Teach Jay deep breathing that he can use when he feels stressed
- Music therapy
  - Pay for services with SSDI or Medicaid
  - Recognize importance of music as source of joy
  - Use music as a method of instruction
  - Use music to enhance self-concept such as performing for others

(continued)

Table 1. (continued)

  - Use music to enhance contribution to others (such as singing to his grandfather when he was receiving Hospice services)
  - Incorporate friends to maximize connections
- Community connections
  - Hang out as a "regular" in preferred settings
  - Become acquainted with owners and other regulars and develop relationships
  - Communicate directly with owner and regulars about support needs, as needed
  - Seek opportunities to reciprocate kindness to owners and regulars
- Transportation
  - Teach use of public transportation
  - Invite public transportation providers to be reliable allies, even participating in some person-centered planning meetings
  - Meet regular riders and teach them to provide support, as needed
  - Consider transportation options when choosing a home
- Church
  - Provide opportunity to greet people on a regular basis
  - Provide support to participate in worship and music, including holiday rituals
  - Provide support to attend church-sponsored social events
- Bedtime and sleep
  - Provide choice on bedtime routine each evening
  - Honor preference to say prayers aloud with family
  - Provide "acceptable options" when unable to sleep (such as watching TV)
  - Encourage personal responsibility for washing wet sheets

not wholly independent, but just needing more support than most others. His and others' regarded-ness then shaped his and their lifestyles.

No one exemplified this "just as I am" reciprocity any more than Tom Riffel. Tom saw everything Jay did as "just Jay," not as a behavior to be shaped but an aspect to be enjoyed. That is not to say that Tom and Laura did not use PBS to create a lifestyle for Jay; they did. It is, instead, to say that shaping behavior through PBS and thus creating a lifestyle depended in very large part on their entering Jay's "world," adopting his view of himself and of the world he wanted, and then acting to create the world Jay wanted.

As Horner and his colleagues (1990) noted, PBS builds access to the preferred life, but that access depends on those who use PBS being willing and able to stand in another person's shoes, see the world from that person's perspective, and then act to create the world the person wants. PBS is most effective when the supporters pass the "shoes" test—when they put themselves in the place of the person they support and try to see the world (and themselves) from that perspective.

Put it in another way: Jay was our best teacher about how to pass the "test" of creating the life he wanted. We and his reliable allies had to "become" Jay and to understand that we and others challenged him, not just that he challenged us.

Anticipation

Tom was a master at knowing just when to offer Jay something extra, some event to anticipate. Anticipation—today's flight to tomorrow's desired end—powerfully shaped Jay's behavior; it became an essential part of the "positive" behavior support. When Jay was depressed, taken down by his bipolarity, Tom would often say, "OK, Jay, let's talk about going to the 'brown hotel.'" Wanting to go to a hotel on a Saturday night, Jay would rise from his bed, willing himself to cope as best he could with his biological depression. Sometimes, it seemed to us, that the anticipation was even more delightful for Jay than the event itself. No doubt, he sensed he was special as he signed into a hotel and gave the desk clerk the money he had earned to pay for some of the costs of his and his friend's room. But simply knowing he would go to the hotel helped him do what he wanted to do but often was thwarted in doing because of his bipolarity. Desire can defeat disability.

Being Engaged

Jay's behavior was more stable when he was engaged. As the tides of bipolarity and limitations of autism and intellectual disability churned his life, engagement became the stabilizing factor, the deep keel that mitigated his challenges. Engagement took various forms: the "big" events of going to a hotel or having his sisters return to visit him, and the "little" events of talking and singing with others, watching TV with his friends, helping do chores in his home, doing his duties at work, seeing the same people at work day after day, and going out to lunch with colleagues or eating with them in the break room.

Idleness too often correlated with problem behavior and a nonmodulated mood, but engagement facilitated just the opposite. Engagement depended on people, nearly two dozen each week, and on their taking the "shoes test" with Jay and then engaging him in the events—hotels, restaurants, errands, and so on—that further engaged him. Anticipation became part of PBS, but the implicit promise of anticipation is engagement. To shape Jay meant shaping his world. It meant promising and then delivering on the promise.

Music

Music was the "balm in Gilead" in Jay's life. It was a source of joy, solace, connection, communication, and energy, among other things. It exacerbated his happiness; it mitigated his depression; it sometimes prevented, sometimes blunted, and sometimes helped him recover from behavioral outbursts.

This meant that everyone involved with Jay had to infuse music into as many of his waking hours as possible. Jay looked forward to music therapy on Monday through Thursday evenings (provided by three different therapists). The music therapists used music not only to provide enjoyment but to teach a variety of skills and to address problem behavior.

His first music therapist, Della Clayton Molloy, composed an "energy-giving" song, titled "Turbo Turnbull," to pump Jay up when he was down; it became his "fight" song, rather much like a university's.

Music mitigated Jay's behaviors in still other ways. For example, Jay regularly emptied bottles of mouthwash, disrupting our bathrooms and routines. We mentioned Jay's behavior to Mike Brownell, another music therapist. Having noticed that Jay loved the Beatles' "Let It Be," Mike adapted the lyrics to describe what Jay would do when he would go into a bathroom and see a bottle of mouthwash: "When I find myself in a bathroom/and see the mouthwash standing there/then I always tell myself/Let it be, let it be!" Who except a music therapist would have thought that The Beatles were elements of PBS? Yet using music to replace problem behavior with appropriate behavior is essentially putting a social story to music.

Invariably, Jay's music therapists became his friends, invited to the many parties that Jay and his housemates hosted, those being part of the reciprocity element of PBS. Every party involved music, Jay leading a rag-tail chorus of his friends and family, accompanied by one or more of the therapists on guitar or piano, singing. Music became not just the balm for Jay but also the common tie that bound us all to him.

Many parties closed with Jay leading us in John Denver's "Annie's Song." More than any other song, "Annie's Song" captured what Jay and we, his parents, and his friends sought, not just for him but for ourselves as well:

> You fill up my senses like a night in the forest/Like the mountains in spring time/
> Like a walk in the rain/Like a storm in the desert/Like a sleepy blue ocean,
> You fill up my senses/Come fill me again.

To "fill" a person—to full-fill a person—is much of what PBS and lifestyle change is all about. But there was more to Jay's life than fulfillment of his senses; there was the ineffable reciprocity:

> Come, let me love you/Let me give my life to you.
> Let me drown in your laughter/Let me die in your arms.
> Let me lay down beside you/Let me always be with you,
> Come, let me love you/Come, love me again.

Fulfillment results from giving and receiving, from reciprocity, from drowning in each other's laughter, from asking simply this: "Come, let me love you"—to give; and this: "Come, love me again"—to receive.

Dignity and PBS

Jay's self-regard—his sense of his worth, his sense that it is right to give and receive—changed how people regarded him. He could not acknowledge his disability; he simply was not smart enough to know that he had significant limitations. But he could and did acknowledge his sense of self: Less able, but not less worthy (H. R. Turnbull, 1976).

It is hard to trace a single origin of his sense of self for there were many: his sisters Amy and Kate and their friends, the people who came into his life and their friends, and us and our friends and colleagues. With so many people answering Jay's call—"Come, let me love you/Come, love me again"—and with so many people utterly intent on standing in Jay's shoes and then following Horner and colleagues' (1990) admonition to create "access to activities, place, people, and events" (p. 129), dignity was inevitable.

On the topic of dignity, we are reminded of another passage from Horner and colleagues' seminal work:

> *Behavioral interventions should maintain and support the personal dignity of the individual*. . . . Because the purpose of behavioral intervention is to assist people in becoming full participants in society, the procedures used to achieve this goal should be within the standards set by society. . . . By its nature, behavioral technology involves continuous on-site technical and ethical judgment. (Horner et al., 1990, p. 129)

Nineteen years after Horner wrote that line, our colleague, Michael Wehmeyer, our deeply respected and valued colleague and friend, eulogized Jay in words that cut to the very jugular of what it means to live a dignified life:

> The lessons Jay imparted were simple, but important in the context of our too often hectic lives. He reminded us to remember the holidays; to revel in family and loved ones; to live life with gusto; and to have favorite foods that excite you. But Jay's ultimate lesson to me came this week. When the press release announcing Jay's death was posted Wednesday night, I paused after I read the link from the KU home page to the news release. That link read: University mourns long-time employee Jay Turnbull.
>
> Think about that for a moment. The headline could just as easily have read "University Mourns son of Distinguished Professors" or "University Mourns Special Worker." Instead the headline points out a simple fact; that Jay was a person in and of himself,

> independent of who his parents were or whether he had a disability. He was a person who worked for 20 years and who contributed to the mission of the Beach Center, the Life Span Institute, the School of Education, and the university.
>
> And in reflecting on that headline, and thinking about Jay and his impact on my life and the lives of others, I realized that the most important lesson Jay taught me was not really about the possible lives people with severe disabilities can lead, that people with severe disabilities could live in their own homes or perform meaningful work or lead a full social life. Those are important lessons, I know, but these lessons are really about the business of education or the rehabilitation business or the business of the myriad of professions that provided the supports that sustained Jay.
>
> No, what Jay taught me, and what I believe he taught so many around the world who join us today to mourn his passing and celebrate his life, was that we are not in the education business or the rehabilitation business, or any other business; we are, each of us, in the dignity business. By the quality of his character and the example of his life, Jay reminds us of the dignity of living full lives; lives rich with friends and family and the dignity of work and the security of home and the joy and gift that is each day. Tennessee Williams wrote that "Life is an unanswered question but let us still believe in the dignity and importance of the question." Because of Jay, I know more about the dignity and importance of every person. I can think of few more important lessons to have imparted or a more important legacy to have left.

Jay died suddenly and unexpectedly. He arose on Wednesday, January 7, made his bed, laid out his clothes for the day, and went to the bathroom to shower. On his way there, Tom asked, "Hey, Jay, what do you want for breakfast?" His answer, and his last word on this earth, was "Waffles."

Think about that short colloquy: A question premised on Jay's choice, and Jay's choice stated. What more could so succinctly make the point that a life of dignity depends on having family and friends who are reliable allies, on marshaling all assets and resources, on having a home of one's own and housemates of one's choosing, and on reciprocal relationships, anticipation, engagement, and music?

Were Horner and colleagues' right? Was the science they promoted a "right" science? Jay would say so. Was Wehmeyer right? Was life not just about education and its fruits, but about dignity? Jay would say so.

Indeed, Jay was the proof that ethically right and clinically effective science and dignity are inseparable. Thank you, Rob, Glen, Bob, Ted, Wayne, Jacki, Rick, and Robert; thank you, Jay, for making that point; and thank you, Laura, Tom, Amy, Nina, and so many others for implementing the science so artfully.

Jay had accomplished his mission, but so too had hundreds of others. He called, "Come, let me love you," and we responded. He called again, "Come, love me again," and we and others did. There is a joyful synchronicity when right science combines with art and results in dignity. Jay and joy: The man is inseparable from the feeling.

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References

Horner, R. H., Dunlap, G., Koegel, R. L., Carr, E. G., Sailor, W., Anderson, J., . . . O'Neill, R. E. (1990). Toward a technology of "nonaversive" behavioral support. *The Association for Persons with Severe Handicaps, 15*, 125–132.

Turnbull, A. P., & Turnbull, H. R. (1990). A tale about lifestyle changes: Comments on toward a technology of "nonaversive" behavioral support. *The Association for Persons with Severe Handicaps, 15*, 142–144.

Turnbull, H. R. (1976). Report of the parents' committee: Families in crises, families at risk. In T. D. Tjossem (Ed.), *Intervention strategies for high risk infants and young children* (pp. 765–772). Baltimore, MD: University Park Press.

Turnbull, H. R., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy Studies, 12*, 133–143.

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