

THE DENTAL PATIENT

by Roy Gerstenberger

Revolutionary Common Sense from Kathie Snow

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In June 2002, I (Kathie Snow) was invited to consult with two service agencies in New Hampshire: Lakes County Regional Services Center in Laconia, led by Rich Crocker, and Community Bridges in Bow, led by Roy Gerstenberger. Rich and Roy are both working diligently to redefine their organizations and develop methods to provide services in ways that promote interdependence and community inclusion of people with disabilities and family members. After I returned home, Roy sent the following article—a story he wrote to share some thoughts with his staff after my visit. I was deeply moved by Roy's thoughts, and he gave his permission to share his story with others. When I asked him to provide a thumbnail sketch of his organization to go with this story, he replied, "Community Bridges is a regional developmental services agency in central New Hampshire, where formal supports are offered to people of all ages within the context of good dialogue, visions of a positive future, and efforts to strengthen a community of hope and hospitality." I think you'll enjoy Roy's story!

I went to see my dentist last week. It wasn't just the usual six-month appointment for cleaning. I had called him a week before to set this up because I was having some real trouble with one tooth. A bad night of aches and pains had convinced me that something was wrong, although there were improvements during the intervening days. My hopes were high that it was just a passing problem. But it didn't turn out that way. About a month earlier he had expressed concern about a small fracture in a back molar, and this was the one that was hurting. At his office, it took just a few minutes to confirm that the tooth had split, and the only option was to remove it. "Are you ready to take care of this today," he asked. I wanted to appear confident and reasonable—no "difficult patient" here—so without any quivering in my voice, I firmly replied, "Yes, let's do it."

Things immediately clicked into a kind of code-speak that was way beyond me. My dentist said things like, "We'll need a couple of 240s and some 210s. And make sure that we have a..." There was a brief silence, and I knew that outside of my limited field of vision, the dentist and his assistant had shifted into nonverbal communication and gestures. This really raised my anxiety.

I like my dentist. And I had just given myself up completely to him. The office had a lot of white. He

wore a white jacket. The radio was tuned to a station that was not objectionable to me. I was comfortably seated and staring up at a picture on the ceiling that was some sort of Bavarian castle next to a list of quotes that, I think, came from a *Chicken Soup for the Soul* book.

If I wanted to run at this point it would have taken me at least 20 seconds just to prop myself up on my elbows and swing my legs down below the high arm rests (which are really *bed rails* disguised as arm rests). In other words, it would have been really easy to stop me. So I was, for all intents and purposes, under my dentist's control.

When you think about it, this is a type of mutual agreement to proceed with temporary roles according to a circular logic. My dentist agrees to wear special clothes and paint his office in a certain way, and I agree to submit entirely to his control so that I can benefit from his apparent expertise—which he must have since I am voluntarily giving into his control.

If I was sitting on the sofa at *his house* and he was wearing a casual shirt, this would have played out differently. I would have been suspicious of his expertise and more questioning of his authority. It probably would have taken a lot longer to describe the procedure and review all of my options. He would have had a patient who was less predictable and less

2 - The Dental Patient

willing to sit still while the procedure was completed. I might have even left and come back later.

Back in the reality of his office, the next step seemed inevitable, yet I still wanted to exert some level of choice—if only for appearance. I gestured to indicate my need to speak and asked, “Is there anything I should be concerned about?” His answer was the response I was both expecting and requesting: “Oh, no. It’s probably been many years since you’ve had this procedure. You’ll feel some pressure, but we’ll have you numbed up, so there won’t be any discomfort.” I really like my dentist.

A few weeks earlier I had a conversation with a parent that reminded me of this experience. Her name is Kathie and she has two kids. One of them—her son, Benjamin—had been given a label when he was very, very young, and the doctor thought it would be good for Benjamin to be seen by some people who specialized in development. This turned out to be a group of physical and occupational therapists who were pretty clear that their services were needed, and they believed Benjamin should take advantage of the state-funded early intervention program.

Being a good, smart, and caring parent, and after hearing about the importance of these services, Kathie jumped into the endeavor. Benjamin’s joints were measured for range of motion, therapy appointments were scheduled throughout the week, the family room was converted to a home therapy area, and the best equipment was purchased. Kathie understood clearly that this was the “right thing” to do.

But after several years of this routine, Kathie stood back a little and saw a different picture. Her son cried, asking not to go to therapy. The hectic pace of appointments had virtually eliminated time for her to do other things with her family, in her neighborhood, or in her community. Therapy became the main focus of family discussions. Kathie’s daughter was getting to know her little brother primarily through the role that she saw him most: as a therapy patient. This

mother believed all these things were a pretty high cost to pay, and she began asking, “If we stop all of this, do I have anything to worry about?”

The answer was predictable: “Yes, if your son stops therapy, his range of motion will decrease and eventually, his potential for walking could disappear entirely.” But this mother was seeing something else disappear: her family life. Even more devastating to her was the realization that she was raising a child who was learning this profound lesson: the world perceived him as not working the right way and he was in constant need of fixing. That this message was coming from his own parents was unbearable to her.

In addition, she realized that because Benjamin was spending so much time and energy in therapy trying to learn to walk, he was actually missing out on other critically important childhood learning activities. Kathie saw an obvious way to avoid this dilemma—she would get him a good wheelchair. But the professionals were clear: giving up on walking could condemn him to being bedridden in his later years. Despite this harsh warning, this mother decided

to do something that was incredibly difficult. She claimed the responsibility to define what a good family life and a healthy child would be, and to make decisions based on her definitions. Then she removed her son from therapy.

We find ourselves in the position of being recipients or consumers of professional service so many times, and the pressure to comply is so powerful that it sometimes feels like other choices are all but eliminated. Think about when you go into a doctor’s office, and the degree to which you comply while there. We will sit for an indeterminate amount of time in a waiting area. We will then, upon command, go to a smaller room to wait for yet another indeterminate period of time. Then we comply with another command to change into an uncomfortable and undignified garment, and sit on an examining table which forces us to dangle our feet like a child as we wait to see the doctor.

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In his book, *The Careless Society*, John McKnight describes this type of relationship as part of a “therapeutic ideology.” He describes three components of this ideology:

The basic problem is you,
the resolution of your problem
is my professional control, and
my control is your help.

McKnight goes on to say, “The essence of the medical ideology is its capacity to hide control behind the magic cloak of therapeutic help.”

This seems to represent the role play and the circular logic which I experienced in the dentist’s office, and which Benjamin experienced with professionals. However, there are two important distinctions between our two sets of experiences. First, the dentist’s control was overt, and it was directed to only one part of my body. Second, I was voluntarily entering into a relationship with a professional who had a very discrete boundary. I would receive the service, and within a very short period of time, I would leave the office and resume my role as father, employer, student, committee member, and spouse. My experience had no residual effect on my lifestyle, and my role as a dental patient would not enter other areas of my life. People would not pass me on the sidewalk and think, “There’s another dental patient.”

This was not so for Benjamin. In order to access the professional services that others said he needed, it was necessary for him to acquire a diagnosis. As most parents learn in this situation, the diagnosis starts out as a key to access help. But rarely, if ever, is the diagnosis discretely limited to the time and place where the help is received. The diagnosis becomes a label that follows you, and it represents a whole series of expectations regarding the life you will lead, as well as the life you will *not* lead. Kathie heard that the problem was her son and that she would not be doing the right thing for him unless she adhered to the professional advice she was given. The ultimate message was this: the resolution of the problem was professional control.

More than one set of parents has described the experience of sitting across the table from a person in the human service industry who announced, “The right thing to do is send your child to an institution and forget about him.” The fortitude required to resist such advice is infinitely greater than what is needed while sitting in the dentist’s chair or lying on the doctor’s examining table. Yet many parents have demonstrated that fortitude.

How can those of us in the human service industry present options for parent support in a way that requires the lowest level of resistance and—as a result—the highest level of autonomy, so parents can be the ultimate decision-makers about the life they want for their family? Kathie described one of the things she wished had happened when her son was young: that services from a human service agency be presented as an *option*, instead of a *mandate*. She said she had learned there are many ways to get what you need for your family and your child who may be developing in a different way, and she figured out

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where those options were in her community. When she was first presented with the standard prescribed list of therapeutic services, no one offered an opinion or a suggestion that the same outcomes could be achieved using other activities in the community or even in her own home.

Kathie also said it would have been really helpful if she had known about the negative impact the traditional early intervention services would have on her son and her family’s life. Consider this: when we get a prescription from a doctor, we learn about the side effects of the medicine or treatment. Why haven’t we applied this standard to the human service industry? We know that such information is valuable:

4 - The Dental Patient

it allows us to learn about unintended consequences and about other options. Then we're able to choose which option is the most tolerable. And, once we choose a remedy or a procedure, we know how to ameliorate the known side effects.

Maybe we haven't done this in the human service industry because there hasn't been legal action to force the disclosure of side effects or other options. However, I like to believe it won't take legal action to force people in the human service industry to do things that are helpful to others. At the same time, it does seem that—to the extent that such disclosures tend to weaken the image of the professional as confident and powerful—there might be a natural tendency to avoid the disclosure of side effects and the presentation of other options. In many ways, this would be equivalent to seeing my dentist in his living room.

To use John McKnight's words, this would represent the removal of the "magic cloak" of therapeutic help. The human service professional will resist it. Disclosure will also be resisted by those who are convinced there is value in being a consumer of the human service industry product; they will make no request for disclosure of side effects or other options. Parents like Kathie are not among them.

When Kathie said she would have appreciated having a clearer understanding of other options from which she could choose, she added that making a choice required her to accept responsibility for the side effects or consequences of that choice. This is not the language of a consumer. It is the language of someone wanting to be an equal in a partnership that is freely chosen. I believe this also implies that, if professional services from the human service industry are requested, the services should be discrete.

Trouble begins when we have the expectation that a professional will know of—and be responsible for—all potential outcomes in a person's life. This is

not realistic. Life can be extremely unpredictable, and life includes pain and suffering. A diagnosis is not a prediction and services are not a guarantee to alleviate pain and suffering.

A trap is set when one person begins to believe that: (1) another person's differences must lead to a diagnosis and treatment, (2) "the problem" is the person, and/or (3) a person's differences are determined to be the cause of pain and suffering as distinct from life itself. The professional industry that provides the diagnoses and treatments seems to believe it can produce consistent success only by exerting maximum control and eventually removing a person from a real life, just as a dentist removes a bad tooth.

This cycle can be broken and it really must be. Parents like Kathie are guides along the path that leads us out of the patient-therapist and producer-consumer relationship. We need to expose the fact that while these relationships may generate cost and benefit to both parties, they eventually lead to entrapment for everyone. Parents like Kathie are guides precisely because they have been down this path and have seen how, at the end, the cost of being an eternal patient or consumer is too high a price to pay.

Many parents are questioning the traditions of the human service industry, and they're seeking balance in their relationships with those in professional services. They want their children to be able to easily and routinely exit the service world and return to their roles as brother, sister, funny kid, committed ball player, loud child at the check-out, or favorite cousin. They want their kids to be kids.

Roy Gerstenberger recently retired from Community Bridges; he will be sorely missed!