

Safeguards Letter

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Considering the Evidence

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*I've just finished reading a newsletter from a state government agency. One article said that it's important to "support evidence-based, high-quality, cost-effective models for intervention services for children with autism and other developmental disabilities...." The article further said that such models are important because they will help us better "coordinate" supports in our state for people with developmental disabilities. I only want to direct gaze on that statement a bit. I don't really want to argue with it. It/its authors may be right. I just want to try to figure out what the statement means and think a bit about what difference agreement with it would make to the ways we try to support people with disabilities. Because I've pondered earlier in *The Safeguards Letter* about "cost-effectiveness" (Summer 1992), I'll skip that here. I want to think about what this "evidence-based practice" means.*

Twenty or so years ago, the statement by the state might well have called for "models" that were "normalized." It was pretty common then for people to attach the idea of normalization—usually undefined and unexplained—to almost every proposal for any kind of service, at least for people with developmental disabilities. Part of my discomfort with the current prominence of "evidence-based practice" (EBP) comes from suspicion that EBP and its twin "best practice" are being used today in about the same way that normalization was used in the past—without explanation or examination. After all, like normalization, "evidence" is something that people seem to think they understand without taking the time to look closer. Today, if you want someone to consider your new idea seriously you'll likely describe it as an evidence-based best practice. But, as was the case with the label of normalization, simple labeling of new proposals as evidence-based isn't enough.

Let's take a look at EBP. To find out its meaning I did what many perfectly respectable 21st century people do. I used Google to consult Wikipedia and to find references to "treatments that work" at a web-site from Oxford University Press. Here's what I learned.

When people are said to have needs that call for intervention, service, or treatment, there's often a choice among methods. That's noticeable in the medical, social-service, or "mental health" arenas. EBP is a way to inform choices in those and other fields. EBP indicates (says Wikipedia) a preference for service measures (treatments) that have been shown to work by means of empirical evidence. Most who rely on EBP to help them decide among service

responses would prefer evidence or empiricism that results from the scientific design known as “randomized clinical trial.” That’s the way that researchers assess the usefulness and safety of new drugs or older drugs for new purposes. Writers about evidence-based practice usually hold up randomized clinical trials as the “gold standard” for empirical practice.

The idea of EBP apparently developed in the fields of medicine and nursing. Then it moved into psychiatry and “mental health,” proceeding later toward influence in other human service areas. The rise of EBP as a determiner of correctness of service measures relates, of course, to the wish of funders of services that the funds they supply be properly used. Those who pay for services—private insurance companies or government agencies like the US Center for Medicare and Medicaid Services (CMS)—want ways by which they can be as certain as possible that payments go for methods that work... measures that help people. Funders also want reasons to reject claims for measures they have doubts about. So, EBP is both meant and used as a way to steer human service organizations and service-users away from practices that have not been professionally approved—in the best of worlds by means of randomized clinical trials.

As far as I can tell, if we rely on EBP to help us determine the right courses of action to take to try to support someone with a developmental disability—which “treatments” to use—we’d have to make at least two commitments. First, we would have to commit to being sure that we knew about the empirical evidence (if any) that supports our choice of approach. We’d all have to be consistent students of current research. We’d have to participate, ourselves, in designing and carrying out research on so-far-unstudied questions that we think are important. Second, we would have to possess tools with which to judge the soundness of the research we study. We’d all have to be experts about research design and implementation. Many would likely argue that these are commitments we all ought to make so that we can know that what we’re doing to support people is right.

The “likely” in the previous sentence is a tip-off that I don’t fully agree. Full reliance on what someone else calls empiricism isn’t always the best way to determine right courses. It’s not just that such reliance means that many potentially useful/helpful measures we might devise would have to await assembly of the required evidence, even though the wait might be a serious drawback. We also have to take into account the frailties of the method by which evidence is collected. Here are three observations, from three different observers, about the limits of science and research.

Ultimately, the most important issues in human services (as in life, politics, economics, religion, etc.) have not been, are not, and never will be decided on the basis of “research,” or even on the basis of empiricism and evidence. They will be settled on the plane of values and ideologies, or even of passion.... The bulk of human services operates in ideological defiance of empiricism. (Wolf Wolfensberger. “Research, empiricism, and the principle of normalization.” In

Robert Flynn and Kathleen Nitsch. Normalization, Social Integration, and Community Services. Baltimore: University Park Press, 1980. Pp. 117-129)

*Science is not superior to its subjects, nor is it inherently superior to the other disciplines. It becomes markedly inferior when it becomes grandiose in its own estimate of itself. In my opinion, science falsifies itself by seeing itself either as a system for the production of marketable ideas or as a romantic quest for some definitive “truth of the universe.” It would do far better to understand itself as a part of a highly diverse effort of human thought, never to be completed, that might actually have the power to make us kinder to one another and to our world. (Wendell Berry, “Is Life a Miracle?” In *Citizenship Papers*. Washington, DC: Shoemaker & Hoard, 2003. Pp. 181-189)*

And, finally, a paragraph that I’ve quoted before. I think it’s imprinted on the inside of my eyelids.

*Science, since people must do it, is a socially-embedded activity. It progresses by hunch, vision, and intuition. Much of its change through time does not record a closer approach to absolute truth, but the alteration of cultural contexts that influence it so strongly. Facts are not pure and unsullied bits of information; culture also influences what we see and how we see it. Theories, moreover, are not inexorable inductions from facts. The most creative theories are often imaginative visions imposed on facts; the source of imagination is also strongly cultural. (Stephen Jay Gould, *The Mismeasure of Man*. New York: W. W. Norton & Company, 1981.)*

Two of those three writers are scientists—Wolfensberger a social scientist and Gould, before his death, a natural scientist. The other writer—Wendell Berry—is a practical scientist, in that he has made his life as a farmer and, thus, as a close observer of the natural world. These writers don’t dismiss science or research. They just want science to be kept within proper boundaries. None of them, I think, endorses the exclusive reliance on research as the sole determiner (“decider”?) of what it is right to do. Science is a human activity. We have to be much more humble about its prospects.

Neither—to return to my original point—is it sensible to decide about what’s right to do in the lives of other people (what Wolf Wolfensberger has called “human management”) on the sole basis of what someone else labels “the evidence.” Assumptions about the evidence too easily become tools of expert or professional control. In 1915 Henry Goddard thought he had the evidence for the inherent criminality of people who, he said, possessed “feble-mindedness.” People with disabilities and those who care about them still live with the results of his miscalculation.

Mere insertion of the phrases “evidence-based” or “best practice” as modifiers in our claims about services means little. Such evidence as we have is not always clear. Much of it changes... sometimes radically. Some evidence turns up in places we didn’t expect. Of course we want the evidence, but it’s never all in, and we’ll always have to keep looking.