

WHAT ADVOCATES HAVE SAID

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Introduction

It was in about 1975, not long after my books on normalization and Citizen Advocacy (Wolfensberger, 1972; Wolfensberger & Zauha, 1973) had come out, that one person mentioned to a second one some other item that I had just published. The second person's jaw dropped, and she said, "You mean he is still alive? I thought he had been dead for ages." As Mark Twain said about himself, the reports of my demise had obviously been greatly exaggerated. Furthermore, we can report instead that even 25 years later, neither Wolfensberger, nor Citizen Advocacy, is dead yet.

This will be one of the most pleasurable speeches about Citizen Advocacy that I have ever given. It is a celebration of 30 years of Citizen Advocacy that is very appropriate to the celebratory context of this congress.

Since the beginning of the Citizen Advocacy movement, I have kept files on issues significant to Citizen Advocacy. With the progress of time, I would add new file topics that seemed to deserve archiving. Among these was one I called "Citizen Advocacy vignettes," i.e., stories about what individual citizen advocates have done. Many of these stories had been told by individual citizen advocates themselves, others by Citizen Advocacy coordinators, or possibly by yet other parties, including some by protégés themselves. A major source of these stories was the newsletters that I received from different Citizen Advocacy offices. Several local offices have had me on their mailing list, so these are naturally the most heavily represented. Later on, many such stories were taken from the Citizen Advocacy Forum, which itself drew heavily on office newsletters. I did not go back to Citizen Advocacy office newsletters in my archives that predated my collecting advocate vignettes, nor did I otherwise go out of my way to elicit or solicit more stories. However, while editing the congress speech for publication, I added a few items that had been published after the congress.

When I gave this presentation at the Citizen Advocacy Congress in Omaha, I remarked that advocate stories I drew on turned out to be almost all from Australia, Canada and the United States. It only struck me when I went through my files that I had hardly any vignettes from Britain. After my presentation, Sally Carr from Citizen Advocacy Information and Training in Britain gave me Paul Williams' 1998 monograph Standing By Me, which I had not seen before. I discovered that it had many parallels to my own presentation, and I subsequently cited some material from it while preparing my speech for publication. However, my report to you will not draw exclusively on published material that ended up in my files, but also on what I remember from such vignettes that did not end up in my files.

Collecting Citizen Advocacy vignettes is a bit like collecting a great many other things from which one can learn something. For instance, there has been a tradition in science, often referred to as the "natural history" approach, of collecting specimens of organisms or science

objects until one has such a large number that one can begin to see which of its individual pieces are of the same class, which are of a different class, what defines certain classes of members, how they can be related to each other, how they can be classified and hierarchically-ordered, etc. For instance, only if one collects a large number of butterflies will one be able to learn which ones belong to a peculiar class, which ones belong to distinct branches of the butterfly family, which ones are merely the same kind of butterfly at different points in a life cycle, etc.

Similarly, there is an enormous amount to be learned from accumulating Citizen Advocacy vignettes, and today I will present, for the first time, some important themes that keep emerging over and over in what advocates have said about their Citizen Advocacy engagements. (More about Williams' (1998) themes later.)

Some of the advocate testimonies I will cite verbatim were authored by advocates themselves, others were authored by people who wrote up an advocate's testimony. In a few of the Citizen Advocacy stories cited, a person was an advocate for two people--usually people who had some connection to each other, or who were members of the same family. This will account for some of the phrasings you will hear.

I documented my stories as best as I could, but in some cases, I had failed to record the source when I collected the item.

Most of the themes that I will cover are not new to most people with extensive familiarity with Citizen Advocacy, but what is new is the systematization that I have given to this material. Also, we can all keep learning from what we already know. This may sound like a paradoxical statement, but there is something very real about it. What I mean is that as individual advocates tell what happened to them, what they learned about their protégé's life, and so on, this constantly keeps reminding us of some important truths, and that some of the things that have been taught as abstractions are very, very real in very real lives, and that they can take a literal infinity of forms.

Some of the Recurring Themes in Citizen Advocate Testimony

Keeping in mind that classifications are arbitrary, it seemed to me that aside from advocates reporting successes and failures, there are five other commonly recurring and overarching themes in advocate testimony, namely: advocate commitment and determination, reciprocity between advocates and protégés, advocates benefitting from the relationship, advocates making various insightful or wise observations, and advocates being grateful for their experience. I divided some of these themes into sub-clusters and sub-sub-clusters.

The single most recurrent of these themes in advocate testimony seemed to be that the advocate had been a major beneficiary of the relationship. And the two benefits that advocates seemed to mention the most are that the advocate learned a lot, and that the advocate has been morally advanced or purified.

I will first sketch each theme, and cite a few typical, and generally short, advocate testimonies about it, and then I will present some mostly longer testimonies that combine several themes. Finally, I will conclude with some overall comments.

However, readers should note that I will not dwell on one of the most common themes of Citizen Advocacy stories alluded to above, namely advocacy "war stories," mostly of successes in having averted disasters, saved lives and limbs, given hope, liberated protégés from institutions, the service system, or other bondages, and on and on. There will be some references to these, but such stories are so common, and already so widely disseminated in the Citizen Advocacy culture and literature, that I am making no effort to retell them here. Interested parties can find many such stories in my files.

Proclamations of Advocate Commitment and Determination

A certain percentage of advocates expressed deep commitment to either their advocacy role, or to their specific protégé, and stated their determination about one or the other. Some examples follow.

"I look at him like he was me, and then I help him" ("Quotes From Citizen Advocates," 1997).

"I've got to be there for him, he has no one else who cares" (Rhall, 1997).

"I just do what needs to be done" ("Quotes From Citizen Advocates," 1997).

"I will do whatever he needs to have done. There's nothing that I won't try to do for him" (Elks, 1999).

"I'd do my best to make sure that wherever he (my protégé) goes he'll get the best treatment possible" (Elks, 1999).

Keep in mind that each quote is from a different advocate.

Once, when a citizen advocate coordinator tried to recruit a citizen as an advocate, he told the citizen about the awful things that were being done to a potential protégé. The citizen was so aroused by this that he blurted out, "This must be stopped!", which motivated him to become an advocate ("Briefly," 1997).

"I will put my foot in any door that is being closed to her" ("Quotes From Citizen Advocates," 1997).

One advocate said about her severely impaired school-age protégé, "I go to all doctor appointments, to all IEP meetings at school, and to all parent-teacher conferences" ("The Testimony of Advocates," 1998). Not even many parents could say this.

One protégé was suddenly rushed to the hospital on an emergency basis due to a serious illness. The advocate (Ellen Horwitz, in Wolfensberger & Zauha, 1972, p. 257), who was a part-time worker and part-time student, "ran home" to cancel some meetings, and subsequently went to see him almost every day, called his room before going to work in the mornings, again

during mid-mornings, and again late in the day between classes, plus she squeezed in several calls to her protégé's doctor over a period of days. She explained why she did all this as follows: "I thought it important for him to know that people are always there, and that I'd be there if he needs anything." Note how often the expression "being there" recurs verbatim in advocate testimonies. In his compilation of advocacy vignettes, Williams (1998) also noted that the phrase "just being there" was very prominent (pp. 6, 24).

"It became important to me for them to have a home, it was personal. I realized that they have to have a home. One way or the other they were going to get a home. I'd spend a long time on the phone. The mortgage people said they were going to give the family a mortgage just to keep me from calling them two and three times a week. One way or the other they were going to get a home" (Elks, 1999).

Sometimes, the proclamation of commitment takes the form of, or is coupled with, an explicit or implied confession of love for the protégé.

"I have given my heart to this relationship with the belief that the stakes are high" (Grable, 1998).

"I love her like a sister and will do everything I can in my power to make it right for her" (Rhall, 1997).

"There is nobody more important than my protégé" (Advocacy Forum, 1978).

"I think she really knows now that I'm her friend, I'm a real friend, I'm a person that cares about her, really cares. She tried to run me away a couple of times. But I hung in there. Lots of people she knew before took advantage of her. Now she realizes that I care, that someone cares" (Elks, 1999).

Some advocate testimony emphasizes the commitment to the long haul.

One advocate told how she found out that her bodily disfigured protégé of nearly eight years was dying of stomach cancer. She got permission to have her protégé leave the hospital for a few hours to visit with her, and when the protégé felt weak, the advocate put her into her own bed to rest. This was noted by the protégé, who giggled, "I'm in your bed!" The advocate walked the rest of the painful way with her protégé, sat by her deathbed, arranged a church service, gave the eulogy, and attended to the burial. None of the relatives attended, deeming it a waste of time (Joan, 1997).

An advocate in England said about his protégé, "I realised people were always coming and going in his life--I had to decide not to be one of those" (Tyne, 1998b).

"I believe I have served and will continue to serve as Mr. Smith's eyes, ears and as his spokesperson. My wife and I desire to do more, and we will in the coming months and years" (Amusan, 2000).

"This is a commitment for life, probably," said an English advocate of a handicapped man who mostly moves around on his bottom. "If things go wrong for him, I'll be there" (Metiuk, 1998c).

One man in Australia became an advocate for another man who had been slipping into dementia. Moved by his protégé's life-long story of marginality, he said, "He's in my life for life" (Kaan, 1999).

"We became friends... I'm just there for him, now and forever" (Stramm, 1998).

"I will always be by her side... She can call me anytime, I will listen, help in any way... She knows I will always be there for her" (Ramana, 1999).

One young man took on the advocacy of a very severely and multiply impaired young girl, who might not live long, and after a year and a half said, "My love for her will never die... I'll make sure in my life she will get the best in her lifetime" (A CA Story, undated).

A Grand Island (Nebraska) advocate said that to her, "being an advocate means...being there whenever I'm needed," and she had 15 years of advocacy presence to prove it (Bockbrader, 1992).

Mind-benighted modernists obsessed with radical autonomy even by severely mentally impaired people keep saying that advocates should only and always do what advisees tell them. If they did, many would cease being advocates because so many wounded persons will initially distrust an advocate, and/or test the advocate by episodes of rejection. The mainstream of the Citizen Advocacy culture has always taught that this will often happen, and that advocates should persist and reiterate their loyalty, and many advocate testimonies demonstrate this.

One advocate broke the wall of initial rejection by her protégé by telling her, "You might be mad at me right now, but I will never abandon you" (Costa, 2001).

A later vignette will tell us of a protégé who repeatedly tried to "run off" her advocate, but where the advocate persevered.

In the Citizen Advocacy movement, we tend to consider it an ideal to recruit an advocate for a needy person for as long as that person is needy, which with retarded people is commonly for life. And because of their multiple vulnerabilities, the life expectancy of mentally retarded people is still much briefer than that of the general population, which is why we generally assume that advocates will outlive their protégés. We are therefore often taken aback when a long-standing relationship ends not with the protégé's death, but with the death of the advocate. For instance, in January 2000, a man passed away in Grand Island, Nebraska, who had been another man's advocate for 25 years. His protégé by that time was 77 (Ayoub, 2000).

One statement of a long-term advocate commitment, even beyond death, is that some advocates have actually included their protégé in their will (e.g., "Kenny," 1982).

Even though people do not always live up to what they say, some do, and some do at least part of the time. And those who make proclamations of commitment and determination are

more apt to live up to them, in that research has shown that once people have made public statements of intent, they feel under greater obligation to live up to them.

Advocates Express a Sense of Reciprocity With Protégés

One common theme found in advocate testimony is that advocates experience their relationship with their protégé as a reciprocal one, often of a friendship nature, as also noted by Williams (1998, p. 6).

Over and over, too often to document here, advocates say, "we have become good friends."

"Getting to know each other is important in our friendship" ... "We have gotten to know each other through many different ways"... "We confide in each other"... "We will grow in our friendship forever" (Rozell, 1998).

"Whenever I'm feeling down, my protégé picks me up."

A Georgia advocate (Mayes, 1999) said about his protégé Amanda, "We are now friends and extended family to each other. When she needs me, I am there for her, forsaking all other business... and forsaking everything else." In turn, "Amanda has come to my side. She has been there for me..."

We can also hear the earlier theme of commitment in many of these statements.

Another advocate (Hall, 2000) said: "I became Joyce's citizen advocate with the idea of helping a young person out. What noble intentions I had back then; never realizing that Joyce and I would come to be friends, confidants and in some ways as close as brother and sister. We have shared the sadness of my marriage ending. There have been days when each of us has rallied the other on for a new job. We have shared the grief and sorrow of the passing of mutual friends. We have also shared the joy of babies being born into the world. There have been financial struggles and small celebrations of debts paid. It doesn't seem possible that I have been Joyce's citizen advocate for fourteen years now! Yes, fourteen years go by quickly, but I think the past fourteen years of my life have been more memorable because of my friendship with Joyce."

"A couple of months ago I picked my protégé up to go play tennis. She got into the car, shut the door, looked me straight in the eye and said, 'I need to know the truth about something; do you take me places and do things with me because you belong to that volunteer thing and it's your duty, or because you like me?' How can I describe in words the happiness I felt to be able to look her right back and answer that we would be friends forever. It was one of the nicest moments of my life, as we sat there face to face. My heart was swelling with warmth and the realization of how much I cared for this person; it came bubbling out, she felt it, and the transformation on her face was like to the sun coming out from behind a cloud" (Avery, 1974).

An English advocate said, "Our relationship is a two-way relationship: we both give and get something out of it" (Kurowski, 1998).

"When Citizen Advocacy is really working, it's about two people helping each other" (Catanzarite, 1997). Lest this become a new dogma, I point out that this needs to be seen as a benefit of Citizen Advocacy, not its purpose.

As Williams (1998, p. 6) noted, "friendship can exist without advocacy, and advocacy without friendship, but many...stories illustrate that the two are closely linked."

Reciprocity is to some degree confounded with some of the other themes yet to be covered, as we shall see.

Advocates Claim Great Benefits to Themselves, and Sometimes Their Families, From Their Advocacy Engagement

Even though Citizen Advocacy was not set up to benefit advocates, but advocates, from the beginning of the Citizen Advocacy movement, I asserted that advocates would benefit greatly from their advocacy engagements, and advocate testimony has amply borne this out. The Citizen Advocacy culture and literature keeps pouring out a virtual flood of testimonials from individual citizen advocates all over the world to the effect that advocates--and sometimes their entire families--benefitted greatly, or even more than their protégés, from their relationship. In fact, this is one of the most persistent themes that keeps coming out of such testimony.

Going through my files, I ran across an early 1972 Citizen Advocacy vignette written by Helen Zauha, the co-author of the 1973 Citizen Advocacy text (Wolfensberger & Zauha, 1973), when she was director of the Citizen Advocacy program of the Greater Omaha Association for Retarded Citizens. Even then, she already mentioned how the relationship she described had proven to be "mutually beneficial" (GOARC Gazette, January or February 1972, p. 11).

I will point out several classes of claimed benefits.

Unspecified or General Benefits

Some advocates will only say that they have benefitted, without going into details how, perhaps because no one asked them to elaborate.

"In a world which values the perfect, the healthy, and the beautiful, we as advocates can make a difference in the lives of people with disabilities. In return, a wonderful difference is made in the life of an advocate by being involved in the life of someone who has a disability" (The Testimony of Advocates, 1998).

As one of the earlier citizen advocates (Mickey Mendez) in Lincoln, Nebraska, put it, "I get a lot of satisfaction out of our relationship" (in Wolfensberger & Zauha, 1973, p. 245).

Two different advocates (Henning, 1998; the Testimony of Advocates, 1998) independently said precisely the same words: "We both benefit from the relationship."

Carol Rap, from Lincoln, Nebraska, the very first citizen advocate ever, once said (I cannot find the ca. 1975 source), "Our lives have been enriched as we have seen the progress Wes has made." Wes had spent 24 years at the state institution for the retarded.

A young lawyer said, "Since I met Nicholas Smith through Citizen Advocacy, my life has been enriched beyond description." "I am fortunate to serve as [his] advocate and his legal guardian of person."

"The best thing about being an advocate is not what we have been able to give...but what Stanley has given us" (Knowles, undated).

"My own family has gained a lot from this experience."

One way that advocates often speak about how they have benefited from their advocacy engagement is by saying, in almost identical words, "My protégé has given me infinitely more than I have given him/her," or "he/she has given me (or done for me) vastly more than the other way around."

"You always get back so much more than you give" (reported by O'Berry, 1999b).

A common phrasing is, "I have been privileged to meet (so-and-so)."

"I don't consider what I do a chore, it's a privilege and I am glad to do it. I am blessed for knowing such a woman."

"I have been Frank's advocate...and have found it to be most rewarding" (An Advocacy Story, 1998).

The phrases "rewarding," "getting more than one gives," "enriching," "enjoy," "fun," "being privileged," "fortunate," and "blessed" or "blessing" are heard over and over in advocate testimony, as you will continue to note in later vignettes.

One early advocate, in Burlington, New Jersey (Ellen Horwitz, in Wolfensberger & Zauha, 1973, p. 257), said about her relationship with a young man who had been in four institutions, "It's been a worthwhile experience for me. I can't tell you how much it means to me... I'm crying... I don't know what else to say." About how many relationships in our lives could we say this?

Many advocates express regret that they did not discover earlier what being an advocate could give to them. They say things like "if I only had known then what I know now" (Cook, 1997), meaning they would have become citizen advocates sooner.

Many advocates spell out more specifically how they feel benefitted, and I have put these stated benefits into a series of sub- and sub-sub-themes.

The Stated Benefit of a Gift of Friendship, Love or Concern From the Protégé

Some advocates are deeply touched by the way their protégé comes to love them and care for them, and see this as a great gift, especially when a protégé had experienced many wounds that might ordinarily have predisposed him/her to never again entrust another person with his/her love.

A Nebraska advocate (Schlueter, 1998) said: "Gary had every reason not to trust me or let me into his life," but "he gave me the gift of love." In reference to Gary's premature death, the

advocate said "He will always be remembered ...and oh so loved." "Would I do it over again? Without a doubt!!!"

Jim Hallberg, one of the first youth advocates in Nebraska, observed that being an advocate was a big boost to his ego because he received "true friendship which is so hard to find..." (in Wolfensberger & Zauha, 1973, p. 253).

One advocate of an older woman had lost her mother at a young age. She came to realize that one of the reasons she enjoyed being with her protégé was that this was comforting to herself, and filled a need to be with a mother-like older woman (reported by O'Berry, 1999b).

"Do you ever wish that you would be accepted for the real you with no strings attached? My friend Kyle can do that for you" (Donna, 1998).

"What a treasure to have affection and joy offered so freely and willingly" (Cook, 1998).

"Steven is 12 years old... we went to see `ET'" (the famous movie) "and... I wept buckets and Steven kept asking if I was alright" (Another CA story, 1983).

Throughout history, observers have noted that mentally retarded persons specifically tend to have a great capacity to love (e.g., Wolfensberger, 1988), and will try to please those whom they love. Sometimes, when virtually every other of their capacities is impaired, they still retain the capacity to love, and to try to be good to the ones they love. Because Citizen Advocacy has made more matches with retarded people than with other needy classes, we hear more testimony along these lines.

The reason I listed the earlier theme of reciprocity with its frequent friendship element separately from this theme is that some advocates discoursed about love and friendship more in terms of it being a gifting by the protégés from which the advocate benefited, even if they may have seen this as a reciprocity.

Advocates Report That They Find Enjoyment and Fun in Their Relationships

One thing many advocates have said in some way or other is that they and their protégés have fun together. As one advocate put it (Rozell, 1998), "we... share many laughs."

One of the early citizen advocates (Julie Meyerson) in Lincoln, Nebraska, was a human service professional who knew that advocates should generally not be sought in such professions, but something surprising happened to her: a 32-year-old man who had spent 16 years in the institution, upon meeting her accidentally, chose her (Meyerson, in Wolfensberger & Zauha, 1973, p. 246)! She reported that she and Ray faced serious problems together, but "Some of the things I have been through with Ray have been funny and we do a lot of laughing together."

"We have great times together."

"We have fun together whether it is just the two of us or in a group" (Tryon, 1974).

A young lawyer brought his protégé to a park, where the protégé ran to the swings. The lawyer joined him, and discovered that he got just about as much enjoyment out of swinging for hours as his protégé, but he would never have done this and discovered it if it had not been for the protégé's initiative (Amusan, 2000).

"I hope other people can have the same experience I am enjoying" (Mary Wynn, Lincoln, Nebraska, Citizen Advocacy program, mid-1970s).

The fun and joy aspect of Citizen Advocacy tells us many important things, such as the following: being an advocate is not all work; at least within the Citizen Advocacy form of social advocacy, the context of advocating does not have to be--and rarely is--all objectivity and a serious goal-orientedness; and it is the expressive relationship element that in most cases carries the instrumental advocacy along, and sustains it.

The Stated Benefit of Learning Important Things From One's Advocacy, or From One's Protégé

One of the most common benefits to themselves that advocates specifically mention is that they learned very important things from their engagement, or from their protégé.

A common phrasing is to the effect, "I have been so fortunate to have so-and-so as part of my life. He/she has taught me so much," or "I learned things from my protégé that he/she would not even know he/she taught me."

A Nebraska advocate in ca. 1975 (I cannot find the source) said about a cerebrally palsied child who was unable to speak or walk, "her enthusiasm and determination have served as an inspiration to me, and hopefully, she has learned as much from me as I have from her."

While some advocates report in a general way that they have learned something from their advocacy engagement, or from their protégé specifically, others will specify what it is that they have learned. This can range across a very wide spectrum, from the mundane to the cosmic. They may say that they learned about, or even completely reversed their ideas about, mental retardation, poverty, human services, their communities, human suffering, the hand of God, and on and on. I have divided the reported learnings into one distinct sub-theme, and a miscellaneous category.

Advocates learn about the darker side of life, society, social devaluation and human services

From the beginning of Citizen Advocacy, I asserted that advocates would learn a lot about the bad things that happened to, and get done to, impaired and lowly people. Not only that, but I also asserted that this is one of the benefits of Citizen Advocacy to advocates, and thereby to society. This assertion has proven to be correct. It is obvious that Citizen Advocacy is a fast and nearly certain way to learn about the darker side of life about which many advocates had

been ignorant, and they do this by finding out what happens to societally devalued people through their protégé. As a result, advocates grow in knowledge, wisdom, compassion, justice, competency and citizenship. While this is very much to their own practical and moral betterment, it contributes in turn to making the world a little less worse than it otherwise would have been.

More specifically, what one hears in advocate testimonies are stories of what we have called the wounds of devalued people. In our teaching (e.g., Wolfensberger, 1998), we speak about 18 common such wounding experiences of devalued people, but these are abstract categories. In real life, these wounds are struck in a virtual infinity of ways, and there is a never-ending novelty in the way an advocate discovers one or more of these many wounds in the life of his/her protégé. At any rate, because human lives are so distinct despite the recurring patterns, I have never gotten bored or weary reading vignettes in which citizen advocates told of learning about these wounds.

One lawyer who had become an advocate said that every time she went to a training session about impaired people and societal attitudes, a light bulb came on in her mind, and "...all of a sudden, I'm saying, 'Oh! Wow! Of course!'" (O'Berry, 1999a).

A Georgia state senator said, "I have always maintained that I benefitted more than (my protégé) because I became more aware of the barriers experienced by many people with disabilities" (Johnson, 1995).

"As Kyle's advocate, my family and I have ...all had another chance to take a long hard look at tolerance and patience..." (Donna, 1998).

"(Being an advocate) has been a really meaningful part of my life. Something I got out of (this relationship) is being able to teach my children to respect everybody, no matter what they look like or who they are. (We) are all the same on the inside. We are all God's creatures..." (Elks, 1999).

In this sub-theme, I also identified three sub-sub-themes.

1. One repeated sub-sub-theme is that the advocate confesses to having been sheltered from contact with devalued people and the bad things that get done to them, and that the advocacy experience shattered this cocoon.

As one privileged citizen advocate (Lowenthal, 1999) said about himself and his mentally retarded protégé William: "We had come from different worlds... My childhood...was spent within the loving embrace of a large family... Opportunities were presented to me throughout my life, while obstacles were present throughout William's... Bouncing from foster home to foster home and finally to an institution had filled William with distrust." "We have touched each other's lives in ways that make us better..."

"When I decided to become an advocate, I was very naive as to what was really happening to many people with handicaps" (Knowles, undated).

"I had no idea about the kinds of things that happen to handicapped people."

2. A second sub-sub-theme is that many people start out assuming that the human service system is benign, facilitative and helpful. What they experience is so often the opposite.

A common type of statement along these lines would be something like, "I had no idea how difficult it would be to...", and then, we commonly get a thumbnail sketch of some horror story, where the advocate was trying to pursue a reasonable--and often even minor--benefit for the protégé, but had innumerable obstacles thrown into his/her way, usually by human service workers.

One advocate in England discovered that "there is nowhere to get good advice about the benefit system" (Tyne, 1998a).

"What I found out about my protégé and the `system' was shocking. The injustice got under my skin" (Jones, 1997).

"I am more aware that the nursing home is the place where I don't want my parents to be" (Elks, 1999).

What many advocates say about their family members benefitting or learning is exemplified by what an advocate's daughter said upon getting to know her mother's protégé. "Just about every assumption I made about Pam and her relationship with my mother turned out to be wrong." Then she recited a long list of her mistaken, and sometimes prejudiced, assumptions and said, "For all these things I am sorry..." She also said, "What I didn't understand then and am only beginning to realize now is that people like Pam need people like my mom and me or they may end up dying... These `types' of people are in real danger of falling through the cracks. Without citizen advocates to protect them, handicapped people are often used and hurt by the system that I had assumed helped them." "Working at Citizen Advocacy has been the best opportunity to learn about myself and others" (Minis, 1998).

3. A third sub-sub-theme is that one way that advocates learn about the realities of social devaluation and wound-striking is that sometimes they come upon a scene where an arm has been raised to strike a devalued person--but the moment the striker perceives that the wounded person is not alone and defenseless, but has an ally from the valued world, the menacing arm withdraws. Advocates keep telling us how often they are surprised that sometimes, merely being with a protégé will open doors to the protégé, even if the advocate says and does nothing. What this teaches advocates about advocacy is the importance of "just being there" for a protégé, quite aside from whatever benefits an advocate may be able to extract by additional actions for a protégé from other parties in the world.

In turn, there is a lesson in this (though not exactly a new one) for Citizen Advocacy offices. Namely, while we certainly want advocates to advocate, we should not dismiss as being of little advocacy value the mere but visible presence of an ally from the valued world by the side of a devalued person.

Of course, the entire theme that everyone can learn from Citizen Advocacy had already been brought out in 1987 by O'Brien's Learning From Citizen Advocacy materials set, in which he specifically emphasized learning about oneself, the community, the service system and the possibilities for people with handicaps.

Miscellaneous other lessons that advocates claim to learn

Some advocate learnings I have put into a miscellaneous category. Here is an example. "I have learned so many things from Theresa" said one Georgia advocate (Abbot, 1999). "Being a citizen advocate has been a profound learning experience for me." She then mentions some of the things she learned. "Helping someone is never just a benign act; help can have an element of harm in it." "...It takes patience and courage to be dependent upon others." "Accepting others' control over you does not have to be the same as giving in." When an advocate discovered that different well-meaning strangers kept giving her protégé the same gifts of shampoo, toiletries and combs until she had chests full of them, she learned that "the gifts that really matter come from people who know us well." "But the most enduring lesson has been that for one person to be truly present with and accepting of another person is ...perhaps the best thing any of us can do for each other."

However, even many miscellaneous learnings reported by advocates fall into certain sub-themes, of which I have identified five.

1. Aside from learning about social devaluation and the realities associated with it, one sub-theme is that advocates voice other things that they learn about human afflictions and impairments. Here are some examples.

"I have learned so much from someone I never thought I could learn anything from."

"People with disabilities want the same thing that I want: a home, real work, friends" (Quotes From Citizen Advocates, 1997).

"Michelle's disability is not the most important part of who she is."

One advocate (Catanzarite, 1997) wrote that while he was not surprised to learn "that people with disabilities have unique personalities and talents," "or that people with disabilities have bad days when they are as whiny, selfish, and hypocritical as I can sometimes be," or that "being a friend to somebody often means biting your tongue, changing your plans, and doing what you should do, instead of just doing what you want to do. None of this comes as a revelation to me. The difference is that, instead of just talking about it, Citizen Advocacy has given me the opportunity to actually put all of this into practice."

"My relationship with Amanda has taught my family and me a lot. The most important thing I have learned was ...that Amanda did not need me to take control of her life, she just needed me in her life" (Mayes, 1999). Of course, there are also instances in which it is very

important that the advocate go further and does take control of what goes on, or others will ride roughshod over the protégé.

An English advocate who is also a human service worker said, "I also work for the local authority, and I have changed because of their plight. I am not as quick to write someone off. I give more time to people with learning disabilities" (Metiuk, 1998a).

2. Another sub-theme is that advocates learn about themselves.

"I learned a lot about myself."

"I had no idea what to expect," but "Citizen Advocacy has been a wonderful opportunity to learn about myself," "...to learn about people."

"I never thought I could do this, and I have been pleasantly surprised to find out what I can accomplish if I set my mind to it."

An English advocate said that no one was listening to his two protégés, and this "helped me find my voice" (Tyne, 1998a).

3. Another sub-theme is learning something about what constitutes the good life.

"It has helped me see that there is much more to life than professional success."

"It has put things in perspective for me, and shown me what is really important."

4. From looking at the lives of their protégés, advocates learn to no longer take some of the positive things in their own lives for granted.

For instance, one advocate said (Rozell, 1998), "She helps me to look at the freedoms that so many of us take for granted in everyday life--the right to have a driver's license, to have a good job and money to buy a car. She must depend on the (paid service worker). I have no staff of people on whom I must depend for the times I need to shop or need to see a doctor. There is no one who is trying to develop an Individual Service Plan for me..."

5. Some protégés teach their advocates to be "gooder."

"Michael teaches me how to be more accepting of people who are different" (Quotes From Citizen Advocates, 1997).

A Nebraska advocate (Schlueter, 1998) said, "[Gary] taught me about patience and acceptance and about appreciation of family."

Jim Hallberg, the youth advocate mentioned earlier, learned something about kindness to the world from his mentally retarded protégé, Wayne. Jim took Wayne out fishing, set him down by the waterside, and observed casually, "naturally, we will fish with worms." But Wayne replied, "You can't kill a worm by sticking it on a hook," and this made Jim fish for the first time in his life with corn--but it was Wayne who caught a fish with corn (in Wolfensberger & Zauha, 1973, p. 253).

"Frank's not the only one benefitting from this relationship--so am I. Since I have been Frank's advocate I have learnt how to be a much stronger and better person." (I think he meant

gooder.) "I now try to confront things and stand up for whom and what I believe" (An Advocacy Story, 1998).

One learning theme drawn to my attention by Barbara Fischer after I had given the presentation on which this manuscript is based was that advocates often point out that their protégé has taught them important truths about being. This in essence makes a protégé a model for his/her advocate, at least in respect to certain issues of being. Examples could be a protégé modelling forbearance, forgiveness, fortitude, etc.

Miscellaneous Other Stated Advocate Benefits

Aside from the benefit themes already mentioned, advocates will also mention specific benefits that do not summate into distinct clusters.

For instance, Carol Rap, the aforementioned world's first ur-citizen advocate, observed that as a result of her family's involvement in advocacy for two young men coming out of the state institution, her whole family benefited, in that they began to do more things together than they previously had ever wished to do, and all this as part of being involved in their relationship to the two young men (in Wolfensberger & Zauha, 1973, p. 248). Similarly, three co-advocates in England reported that their joint advocacy relationship with a handicapped man "brought us out of ourselves, gives us a reason to go about," and visit worthwhile places that they would otherwise never have thought of doing. "...We all get something out of the relationship" (Metiuk, 1998b).

An English advocate said, "It has been very rewarding. It's about trying to redress the imbalance/inequality I see in others: to level the playing field a bit" (Metiuk, 1998a).

Advocates Making Insightful or Wise Observations

Some of the things that some citizen advocates have said fall into the category of deeply insightful or wise observations, perhaps about a protégé's experience, and it is not clear whether the advocates were thusly wise to begin with, or learned wisdoms from their advocacy engagement.

An example is what one of the earliest advocates in Lincoln, Nebraska--namely Ruth Hall, herself a parent of a retarded son--said about her protégé, Barbara Jones (in Wolfensberger & Zauha, 1973, p. 244). She noted that as an orphan, Barbara had been put into the institution at age two with a doll on her arm--and 38 years later, this is how she came out, "just as she had gone in."

Observations such as these seem to be vastly more likely to come from a decent, wise, observant, ordinary citizen than from a human service worker whose mind has been turned upside down by his/her professional training and culture.

Advocates Express Gratitude For Their Advocacy Experience to the Citizen Advocacy Office or Their Protégé

Not only do advocates keep saying that they benefitted from being advocates, but they also often express their gratitude--sometimes to their protégé, and often to a Citizen Advocacy coordinator or office--for having been asked to be a citizen advocate, or for having been matched to their particular protégé.

One relatively new Citizen Advocacy staff member (Finney, 1999a & b) reported being struck speechless the first time an advocate said, "thank you so much for allowing me to do this." My guess is that she will hear this many more times. At any rate, her response was to write to all the advocates, "Thank you so much for allowing me to do this."

In some cultures, there has existed an imperative to help at least members of one's own clan or tribe. Where Western cultural traditions are still strong, people sense a strong imperative to help anyone in need. In turn, many people have realized that it is by being in an individual Citizen Advocacy relationship that they can live out this imperative in a way that is very harmonious with their ideals. This was expressed by Gayle Johnston, one of the earliest Canadian citizen advocates who advocated for a mentally limited married woman, and often met both with her and her equally limited husband. She said this (in Wolfensberger & Zauha, 1973, p. 254): "They visit me at the office, or we meet downtown at a restaurant in Kingston and have coffee and talk. We've discussed a lot of problems and are becoming good friends. I've been able to help them in some ways and they've helped me. I would like to thank them for letting me help somebody because this is important to me and I'm glad there is somebody who will accept anything I can do for them." Thus, we have here both the themes of reciprocity and gratitude.

Also early in the Citizen Advocacy movement, Agnes Deacon became an advocate for an elderly married couple and said, "I think they have done just as much for me as I have done for them...I think it is something everyone should be interested in or get involved with because you don't only help but also get helped," and then she thanked the local Citizen Advocacy director for recruiting her. By the way, she was also one of the early matches made in which the protégés were not mentally retarded (in Wolfensberger & Zauha, 1973, p. 258).

"I would like to thank Citizen Advocacy" (meaning the local office) "for putting me together with Dan...and the attorney who helped me get full guardianship so Dan could move" (meaning closer to the guardian) ("Bill and Dan," 1998). By the way, this advocate was the first person who had stayed for any length of time in Dan's life.

Multiple Themes in Advocate Testimonies

Some advocates voice not merely one but several of the above themes, and sometimes they manage to do this with great economy of words. We have many examples of such theme bundles.

Note how the themes of benefiting and learning are expressed in these few words: "I've benefitted as much from being her advocate as ...she's benefitted from it... I've learned a lot" (from Elks, 1999).

"Jenny was in a living situation that was not only unclean and unhealthy, but also very unsafe--it was, in fact, life-threatening... As long as I am Jenny's advocate, she (or her children) will never live in a life-threatening situation again...the benefits of our relationship do not stop there. I started out... thinking that I was the one that was going to be helping her, but in essence, I found that I received a blessing far greater than I could ever give" (Kubik, 1997). The themes here are determination and benefiting.

"I have learned things from Sara that I guess she would not even know that she has taught me...how everyone has a place and has something valuable to contribute. I've overcome many fears, especially in regards to people with disabilities... I believe that I have been very lucky to have Sara as part of my life... I hope our relationship will continue to grow... It's all part of the growth process for not only Sara, but for me too" (Puntillo, 1998). The themes are benefitting, learning and gratitude.

"We really enjoy each other" said a Nebraska advocate (ca. 1975) for two young women. "We enjoy talking to each other. I sincerely enjoy being with (them). Both of these girls have given me an extra ray of sunshine. They always add a smile to my day. A friend is a dear person who cares about you who shares your life, and who loves you. Diane and Paula are wonderful friends." The themes are sharing joy, a gift of love, and reciprocity.

An English advocate said, "He's a better teacher than I, but I'm learning. He's more sociable than I am, and has made me many friends. We have a lot of fun together, and I think he feels the same way too" (Tyne, 1998b). We see here the themes of reciprocity, benefitting, and having fun.

"James has truly been a blessing to me and to my two daughters. Through knowing James and his family, my girls have a much deeper appreciation for their own family and life-style. We have all learned to look outward and to feel true happiness in making someone else smile. If it weren't for Citizen Advocacy, I never would have met James and his family, so I thank Moira and Mary for encouraging me to become a part of the program" (Ott, 1996). The themes are that the whole family benefitted, and gratitude.

"Despite the benefits to Sam as a result of our relationship, I think it not an exaggeration to say that I have benefitted as much or more. His truly difficult situation, and the great dignity and courage that he shows in rising to his challenges are a constant reminder not to whine too much about my own problems. His struggles put my own difficulties in perspective, and help them seem much more manageable. Often, I find myself saying, 'If Sam can overcome such adversity, surely I should be able to do as well.' His situation also helps me to see deeply into the details of the poverty surrounding many people in my community. As a result, I am a far

more effective local citizen when working in various volunteer capacities to address pressing local issues of poverty and economic development. Actually, Sam and his story have become an important story that my family participates in. I have seen how his struggles have helped deepen the understanding of the vicious cycle that marginalized people find themselves in and thus have helped sharpen my children's values related to tolerance, compassion, and caring. As a father, this kind of lesson is a crucial resource in raising my children to become good and just human beings" ("Sam and Matt," 1999). The themes are personal and family benefitting and learning, learning about oneself, and insight into devaluation.

"I'm a citizen advocate for 13-year-old Lisa... I've learned a lot from Lisa and I feel she has learned a lot from me, you might say we're a little like sisters" (Lincoln Citizen Advocacy program, ca. 1975). Themes here are learning and an implied commitment based on a reciprocal love.

The first time a young lawyer visited an institution ward, and looked in the eyes of a severely crippled, deaf and profoundly retarded little boy institutionalized from early age, who was a member of a class that the lawyer was to represent, the lawyer read the question, "Are you the one?" that reverberated in his mind ever since. He began to spend regular, and ever more intimate, time with the little boy, and discovered that each had become "the one" to the other. "I realized then that the relationship had shifted, and Vince had become a friend. A friend better in so many ways than many of my other friendships that were built on doing things together. For us, simply being together brought peace.

"But even beyond that, Vince had become a mentor and a teacher for me. He taught me the real meaning of patience, since most of his life has been spent waiting. He taught me the value of humor. ...Most importantly his quiet strength and dignity taught me that every person deserves respect, simply because they are a person." Eventually, Vince was moved into his own home as a neighbor to the lawyer (Nash, 2000). The themes here are reciprocity and much learning.

Another lawyer said, "I was sheltered from many of life's unpleasant or unfortunate realities... I have learned a lot. Tom has helped me gain a different perspective on my life. I have seen the day-to-day struggles Tom faces, and I realize how much in my life I have taken for granted. Being a citizen advocate for Tom has taught me how to remove myself from my own hectic schedule and appreciate what is really important." He also said, "Tom and I have done a lot of laughing..." (Villalobos, 1996). The themes are insight into devaluation, learning, and having fun.

"Ted has been a godsend in my life." "My relationship with Ted has changed my perspective... Our friendship certainly isn't a one-way deal. It's one that will last for a long time... I expect we will always be there for each other" ("Mike and Ted," 1997). The themes here are commitment, reciprocity and insight into devaluation.

"I never understood that my ignorance perpetuates the stereotypes attached to people with disabilities... I never knew how our legal, health, insurance, and whatever other systems affect people who function a little differently than me. And I certainly never realized those systems could/should be changed, or at least influenced, to make the world friendlier for all of us... We all want and need respect and love. We also need to give these gifts. Pat has helped me learn this. I feel very lucky... By spending time with Pat, I have learned to reach out, listen, share, and empathize. These are powerful skills. If I learned them as a child, I have had to re-learn them as an adult. And the learning never stops. But this makes me feel hopeful because the lens through which I see is more clear and bright... Pat, one person, has changed my way of thinking. That's powerful... Pat has given me a wonderful gift" (Holland, 1996). Themes are insight into devaluation, and learning.

An advocate guardian (Karelynn, 1998) from Australia wrote this. "I was privileged to be introduced to Pam... ...I've learned a great deal through my relationship with Pam. My son and friends have also learned a great deal and, I must say, are better people to be aware of differences, but not regard people's differences as a deficit. I think Pam and I serve each other... I consider Pam to be part of my family... Pam always says, 'I love you, Karelynn' ...I love Pam, too! ...I want for Pam what I would like for myself... She never fails to help me release the tension... The hug, the kiss." Themes here are learning, one's family and friends benefitting, reciprocity, and implied commitment based on love.

Lola, an advocate in Massachusetts, had a very stormy off-and-on-again relationship with Marianne who virtually personified the wounds module taught in Social Role Valorization workshops. After three years, Lola was able to say, "Although our relationship had had its ups and downs, Marianne has given me many gifts. I have gained the privilege of her trust, learned the true meaning of courage, and shared the joy of watching her improve her life" (North Quabbin Citizen Advocacy News, Spring/Summer 1998). Themes here are benefitting, learning about life, and being gifted by the protégé with trust, after a lifetime of wounds and betrayals.

An advocate from Georgia said about her severely impaired protégé Jerry, who lives in a nursing home, "We have fun." She reported in delight that after treating her as a stranger, he began to reach out to touch her, and put his head on her shoulder.

"I saw how (the Citizen Advocacy coordinator) handled getting the wheelchair in and out of the car, and I thought to myself, 'Oh my God, I'll be lying on the concrete with the wheelchair on top of me!' Now I think I wouldn't care if I fell on the concrete. I'd probably just laugh." Commenting on his deprived situation, she said with determination, "Jerry is going to be in school and in a good home. I'm going to saty on it" (O'Berry, 2000).

Some advocate testimonies are virtual grand slams or dense packs of theme combinations. Here are a few examples.

"We have enjoyed many wonderful times together" said an Australian advocate of over six years (Rose, 1998). "He has taught me so much. It has been a very rewarding experience for me and my family. I will always be ready to defend Ian... Thank you Illawarra Citizen Advocacy for bringing us together. Thank you Ian for being such a wonderful caring friend." The themes in just these few words are reciprocity, learning, benefit to family, commitment and gratitude.

"Leanne has lived her entire life in institutions of varying brutality and she now lives in a government-run group home. She has had a hard life, and still does, that is controlled by a large uncaring bureaucracy. As long as her life is controlled by services there will be the need for someone to watch out for her... Leanne lives in a state of ongoing vulnerability... There will never be a time in her life when there will not be the need for me to be there as her advocate.... Being a citizen advocate can be tough! There have been times when I have not known how to continue." "There have been times when I felt completely overwhelmed by the situations that I have had to face as a result of being Leanne's advocate...the one thing that keeps me going when I don't believe that I can continue, is Leanne herself." "As a result of becoming involved in her life and seeing the awful magnitude of truly terrible things that have been done to her, I have come to respect and admire her strength of spirit and ability to just live life. The fact that she is able to do this with such motivation and hopeful energy inspires me. By standing beside her and fighting her fights I have come to deeply care for her. This has become my motivation for hanging in there when the going gets really tough. Now I can't ever imagine not being there for her." "At the end of the day, I can honestly say that I have gained so much from fighting those fights and being there when things have been so hard. I have learnt a lot about myself and gained a truly remarkable friend" (Stelc, 1997). We hear the themes of insight into devaluation, commitment, reciprocity and learning.

What a Massachusetts advocate said almost sounds as if she had read this article or heard the speech version of it. At first reluctant to become an advocate, upon meeting her 13-year-old protégé Jennifer, "You had me from hello" (citing a song). "Building a friendship together has become an experience full of learning, growth, and commitment." "My fondness and commitment to Jennifer continues to grow." "I am sincerely honored to have become a part of a program filled with such integrity, hope, dedication and compassion as the North Quaabin Citizen Advocacy stands for..." "As for Jennifer and I, we anticipate that our friendship will continue to grow and blossom and that in the future, we will continue to share the many up and down phases of both her life and mine" ("Pat and Jennifer," 2001).

Overall Comments and Conclusion

In the way of conclusion, I will now say something on the topic overall.

There are a number of things I did not do, or lay no claim to.

1. The sources that I cited are not to be considered the only ones to support my claims. To some degree, I also drew on my memory of advocacy stories that I heard.

2. Much as natural history collections can be credibly and usefully classified in more than one way, so I am not asserting that my classification of themes of advocate testimony is the only, or the best one.

3. I also repeat that most of the themes I brought out are not new. For instance, even in the early 1970s, I used a teaching overhead that listed "satisfaction in serving others," "increased self-awareness," and "knowledge of societal processes and needs" as advocate benefits. "Increased acceptance or tolerance of differentness," often mentioned by advocates, I had listed as a societal benefit. Later, several other benefits were added, and in recent years, A. J. Hildebrand has used a set of teaching overheads listing most or all of the themes mentioned here as benefits either to advocates or to society.

4. I make no claim to an exhaustive delineation of themes. In fact, after I spoke to the Omaha congress, Paul Williams' monograph (1998) was brought to my attention in which he also brought out advocate themes in a different way, some of those themes overlapping with my arrangement here. The more vignettes one reads, the more themes are likely to become apparent. However, the delineation of certain themes may require more focussed interviewing of advocates. For instance, one often hears advocates say that their protégé is "an important part of my life" (Quotes From Citizen Advocates, 1997), or "plays an important part in my life" (Henning, 1998). This could refer to reciprocity, friendship, or commitment, but could also mean something distinctly different about which one might have to interrogate the advocate.

5. Though reading advocate stories can become addictive, after some time, one discovers that so many advocates keep saying the same things that time to document them all becomes a bottomless pit. It would quickly become tedious to write down, several hundred times, things like "I learned a lot," "I got more than I gave," etc. Thus, at a certain point I gave up documenting further vignettes that merely buttressed the delineation of the above themes. For instance, I already mentioned that I decided not to dwell on the most common theme of all, which is something along the lines of "I got engaged as a Citizen Advocate, and managed to do a lot of good for my protégé." I call these "war stories of success." I also did not make a point of bringing out a common theme of advocates saying that at first, "I didn't know what to expect," and "I was rather nervous about our first meeting."

I want to pay tribute to Paul Williams for his collection of 38 advocacy stories (1998). While many of the stories were not first-person accounts, and many of the advocates had not been advocates for long, and a number were human service workers, there was nevertheless a gratifying overlap in the themes he identified with those here, as already noted. For instance, he named the themes of "mutual benefit to both advocate and partner," "partner being enabled to give to advocate," "sticking with it over the long-term," "surprise at uncaring systems," and "just

being there (existence of advocate is helpus even without action)." Williams also included two pages of advice on collecting and using advocacy stories.

Once some of the themes are clearly established in one's mind, one also begins to see them in less articulated form, or expressed between the lines. Examples are expressions of reciprocity, and of gratitude for having been recruited. One is then left with the conviction that if one had asked, "Is this what you meant to say," one would in most cases get an enthusiastic "of course, that is exactly what I meant."

Nevertheless, even when one does encounter a theme that one is familiar with, one may not recognize it right away because of the way it is phrased, and/or embedded in the text. I found that I sometimes had to stare at a vignette for some time, or repeatedly, before recognizing a familiar theme that had been embedded in it all along. This being the case, it occurred to me only after I had read scores of advocate vignettes that I had put into my files, and extracted material from them, that I should go back and look at some vignettes from before the time when I began to put such stories into a distinct file. So I went back and took another look at the vignettes that Helen Zauha and I had put into our Citizen Advocacy text that had been published in 1973 (Wolfensberger & Zauha, 1973). Of course, these testimonials predated the 1973 text, and thus were from some of the earliest Citizen Advocacy relationships. Nevertheless, many of the themes that I have pointed to here could already then be discerned. For instance, already then, when the longest advocacy relationships were only about two years old, one could already encounter statements of advocates learning, benefiting more than their protégés, and being grateful for having been recruited.

I hope that one of the services I have rendered is to illustrate the variety of ways advocates may express a theme, so that from now on, when you hear advocates telling stories, these themes will more readily spring out at you from their background.

Among other uses of this material, I also see the possibility that Citizen Advocacy offices may want to draw on it in service of their fund-raising efforts. Vignettes of what people in Citizen Advocacy do and say are, in my opinion, extremely powerful in convincing people of the merits of this undertaking.

Another contextual observation is that in the Citizen Advocacy literature (and my files), one will also find (as mentioned before) many stories told by Citizen Advocacy personnel, and by protégés, and someone may some day want to take a systematic look at these. However, in the things written or said by Citizen Advocacy personnel and closely-associated observers, one will also find that they say the same things as advocates, i.e., that they benefitted, learned, grew, were grateful, etc.

For instance, one Citizen Advocacy coordinator (Rhall, 1998) reported this. "A group of advocates recently met together to talk about their advocacy roles and the common issues they faced. It was a fairly laid-back evening held together by chocolate and carrot cake, yet the

beauty and intensity of the evening lay in the recollection and sharing of their respective stories. To listen and hear the sometimes challenging, sometimes hilarious, sometimes frustrating and sometimes downright impossible experiences of these advocates in their advocacy relationships was for me a profound and moving opportunity."

Before taking on the position of coordinator of the Grand Island (Nebraska) Citizen Advocacy office, a woman had had 27 years of experience as a mother, and a lot with services and systems, and she thought that she knew much about all this. But she confessed (Cook, 2000) that it was the Citizen Advocacy job that brought home to her how much vulnerable people are financially exploited, sexually abused, and mismanaged by the service system.

Another Citizen Advocacy coordinator (Bialecki, 1998) said, "Some advocates have thanked me for inviting them to become advocates. These are often advocates who are standing with people with disabilities as they face difficult situations, confront systems, and deal with painful histories. In their willingness to touch and be touched by the vulnerability of another, they come to understand themselves and the world differently... The hope and trust I've met in people whose lives have been colored by pain and suffering has been a great gift to me. Their ability to endure their suffering and emerge as people who are not bitter, but hopeful, inspires me and builds my own sense of hope." Another coordinator said, "It's an honor and a privilege to get people connected."

Now I want to say some things about reading hundreds of advocate testimonies slowly and thoughtfully in a concentrated fashion over a period of several days, instead of reading a vignette here and there over a period of years or even decades. Namely, this makes a very different impact on one and will affect one differently, and enables one to learn--or at least explicate--certain things, which I will now do.

One such thing is that in most cases, advocate testimony does not come as professional technical discourse, but as ordinary people-talk. It does not come with punctuation marks and perfect spelling, and is often not well-organized. It also tends to be laconic, i.e., it commonly tells a great deal in just a few terse words, as many of my citations have already illustrated.

One lesson from reading hundreds of advocacy vignettes is that Citizen Advocacy staff should exercise discretion as to when they themselves should tell an advocate's story, and when they should let the advocate do it, which of course may require setting a proper stage for it, such as an interview, or some public forum. There is a time for each, but some advocacy newsletters carry many first-person advocate stories, and others carry almost only vignettes written by observers. Stories told by Citizen Advocacy people tend to be well organized, well written, well spelled and punctuated, and often gripping and well interpreted. However, something also tends to get lost as compared to the advocate's own words--perhaps unpolished, poorly organized, and laconic, and yet with such a ring of truth, and so compelling. Many of the things that they say are apt to be edited out if someone else wrote their story.

Another thing I noticed is that there was a shift in emphasis over the years, from a lot of expressive involvement with instrumental "doing for" and direct helping, to a greater emphasis on the instrumental "advocating for," but apparently without any loss of the expressive element. As late as 1983 (Wolfensberger, 1983) I had lamented that Citizen Advocacy offices were recruiting too much with an appeal to the expressive element in the relationship, and that this was pushing the instrumental advocacy and representational element to the edge. While in later vignettes, we find that the expressive element is as strong as ever, we also find that the instrumental functions performed by advocates had shifted significantly from helping and doing-for to representing and advocating. I ascribe this difference in part to more resources being available that one can advocate for rather than having to provide them, in part to the spirit of the times, and in part to the evolving maturity of the Citizen Advocacy culture and the offices, in that office personnel have learned to ask more searching questions about the needs of devalued persons, and have in turn brought these needs more clearly to the consciousness of advocates. In fact, many Citizen Advocacy offices now approach potential advocates with a much more explicated description of the plight and needs of a potential protégé.

While the early advocacies may have been overbalanced with expressive elements in relation to the advocative one, reading hundreds of advocate testimonies brings out how important the expressive element is in supporting the instrumental and advocative ones. I have always believed that purely instrumental advocacy can be effective; but it is difficult to sustain if the advocate does not develop an affective bond with the protégé, and without that affective bond, many advocates would have difficulty even discerning what is right and best for the protégé. The affection enables them to increase in empathy, and thereby to develop important insights into their protégé.

That many advocates grow in such a way into their relationship with their protégé--even if they do not say it--is one of the more obvious facts about Citizen Advocacy. One only needs to read advocacy stories such as the one in Stephenson's (1983) book, Roxene.

While I did not endeavor to dwell on advocate success stories, I briefly want to mention two benefits to protégés that become apparent not only from advocacy vignettes and advocate testimony, but also from observation of Citizen Advocacy relationships.

One is that research study after research study has shown that regardless of how favorable the living situation of handicapped people in the community may be, the one thing that is lacking--and almost invariably so for mentally retarded people--is genuine social integration. However, as far as I know, none of these studies have compared people who have citizen advocates with those who do not, yet judging from the vast informal literature on Citizen Advocacy, it seems virtually self-evident that it is retarded persons with citizen advocates who, in fact, are more likely to experience various degrees of integration. A great deal of this integration results from protégés so often being first included in the family life and events of advocates, and

derivatively in the activities of the advocate and the advocate's family in the community. Since in most cases, the advocate is from a valued sector of the population, the protégé then generally also gets drawn into valued physical and social contexts, and into valued activities. We hear this expressed when advocates tell us that their protégé is often with them when they do this or that in open society, and in contact with colleagues or others. As one advocate said, "My family included him...it was just natural to include him in my daily life and also with my family and friends" (Schlueter, 1998). Further, advocates commonly mediate yet other contacts between their protégés and the members and activities of society. For example, the advocate just mentioned effected a reunion of her protégé with his family in his former hometown, and a visit to his boyhood farm.

Another thing that struck me in reading hundreds of vignettes in just a few days was just how creative advocates have been in seeking benefits for their protégés. Often, they would notice a problem or need--even a subtle one--and then come up with things to try that would never have occurred to me, but that usually were commonsensical and often very simple, drawing on resources that one might not think of even though they are readily available. For instance, if one's protégé was a child whose speech was minimal because of numerous ear infections, one might think of all sorts of recourses to pursue, but would one have thought of going with the child to the public library when story-telling times were being offered there (Ott, 1996)? Some of us would not even have known that there was such a thing as story-telling in public libraries.

As mentioned at the beginning: two of the most common themes of citizen advocate testimony are that advocates benefit as much or more than their protégés, and that they are glad and grateful that they somehow got involved either as a citizen advocate generally, or in the relationship to their particular protégé.

Along these lines, one thing that struck me was that while all sorts of benefits to advocates had been predicted even before the first advocate was ever recruited, I had discoursed about such benefits in the abstract, and had failed to anticipate that advocates themselves would spell out all the benefits they received from their advocacy engagements. For instance, I do not recall it ever occurring to me that any advocate--let alone hundreds of them--would actually say a thing such as, "I received vastly more from my protégé than I ever gave him/her."

One of the reasons for this was, of course, lack of experience, but another was probably that the earliest roots of Citizen Advocacy were in 1967, which was still in an age of paternalism, and where there was an expectation that many advocates would function in a parent-like role to their protégés after the protégé's own parents had passed away. Unlike the modernists of today, I have never thought that paternalism was a bad thing, only that it needed to take into proper account the capabilities and age of a protégé. However, the point is that from a paternalistic

perspective, one thinks first and foremost of the benefits for the protégé, not of those for the protector.

I must say that even though the theme of advocates feeling benefitted was thoroughly familiar to me, I was deeply moved to see this expressed over and over, in some way or other, in story after story.

One obvious benefit of Citizen Advocacy is that it has a way of bringing out the very best in so many people who have undertaken to be citizen advocates, even if they themselves do not say it. About how many human enterprises can one say this? Not about commerce, not about science, not about becoming educated, not about all sorts of enterprises, and not even about most positions in paid human services. It is thus amazing how much good Citizen Advocacy can bring out of so many people.

Particularly in regard to the benefits to themselves explicitly claimed by advocates, when one hears these mentioned by them the first few times, one may be surprised and/or gratified, and perhaps say to oneself that real life has validated what theory had predicted, such as that volunteers would indeed step forward, that they would act in the interests of their protégé as they perceived these, that not only protégés but also the advocates would benefit, etc. But when one hears so many advocates in so many different places from all over the world saying some of the same things about how they have benefitted, and say it over and over quite independently of each other, one cannot help but be deeply moved about something very important going on and being said. After all, as far as I know, no one has been coaching the citizen advocates from all over the world to keep saying the same things, nor am I aware that there is a conspiracy among advocates to do this of which the leadership of the Citizen Advocacy movement has not been aware. Thus, we can conclude that we are seeing a universal phenomenon that has the capacity to exert a powerful transformative impact on advocates in a world where people and everything else are falling apart. One could almost say (tongue in cheek, of course), "forget about the benefits of Citizen Advocacy to protégés, because the benefits accrued by advocates alone are worth the whole enterprise."

Now I have a very important point to make about one specific benefit to advocates. Many of you have heard me say that I believe that one's soul comes into serious jeopardy if one does not walk closely with some of the least of society. There are many ways through which such a closer walk can be achieved, and Citizen Advocacy is one of several means for mediating such closeness.

Closeness to a lowly person can upset one's worldview, and most of all so if one acts as that person's protector or advocate. One begins to see the world from the bottom up instead of from the top down (e.g., Wolfensberger, 1989).

Many of us have seen politically conservative and/or wealthy people become radicalized in most marvelous ways through their close relationship with a lowly person. Only through this

relationship did they come to understand, bit-by-bit and step-by-step, and sometimes with incredulity and amazement, that bad things do not merely happen to lowly people, or are brought upon them by their own behavior, but get systematically done to them as part of a process of oppression that they did nothing to deserve. This can be a very radicalizing experience, and to observe a privileged person getting thusly educated and radicalized can be very amusing. It has often given me the kind of laugh where my insides slowly shake, sometimes from trying not to reveal my amusement.

In this connection it struck me that one class of people who seemed to have been among the best learners and benefitters along these lines were lawyers who became citizen advocates--or at least, they were more likely to tell their stories. At any rate, how fortunate they were!

To underline the point being made, I present one more vignette (Forum, 1998). A privileged Savannah woman who had never been involved in what she called "social movements," and had never been around a handicapped person, was gently lassoed by Tom Kohler, the director of the Chatham Savannah Citizen Advocacy office, into an advocacy for a blind woman. After being an advocate for 16 years(!), she had this to say. "...Charlene is someone with whom I never probably would have crossed paths. We don't have a lot of common interests. Our circles of friends are very different." Then the woman explained in bits and pieces that she tried to learn as much as she could about Charlene's world, that "it has been an eye-opening experience for me," that there was much "soul-searching," that her involvement with Charlene had not been easy for her, turned her worldview upside down and "had helped me personally." She said both that "you get so much more out of it than you put in," and that Charlene gave her more than she gave Charlene. It brought her closer to "the kind of life that I'm supposed to be leading" as a Christian. "I came to understand what she had to do on a daily basis just to get by. That was probably the hardest thing for me to understand." Yes, she said, "it's one thing to write a check to some nonprofit organization and send it off, but it's another thing to get called in the middle of the night when somebody is upset." She also reported that her daughter grew up with Charlene around and now has none of the problems with bridging worlds that she had had, and as a result, the daughter "will be a more well-rounded person." One other thing all this led to was that "most everybody I've worked with has seen me with Charlene, and becomes more aware," bridging their worlds a bit; plus she ended up serving on the Citizen Advocacy board for about eight years, recruiting a number of other people as advocates. On the one hand, I could not quit chuckling when reading this; on the other hand, it was like observing soul-saving in slow motion, and seeing blessings bestowed on a person's entire household. I also thought, this woman's story sounds like something the Southern novelist, Flannery O'Connor, might have told.

The soul-saving potential of engaging oneself as an advocate for a lowly and oppressed person has an implication to Citizen Advocacy offices that I have to explain in a bit round-about

fashion. Namely, there is one remarkable fact about Citizen Advocacy that is rarely underlined in the Citizen Advocacy literature. It is that citizen advocates do, in fact, come from virtually every sector of society: male and female; from every race and from a vast number of national origins; and perhaps most important of all, from rich to poor, and everywhere along the political spectrum, from liberal to conservative. When one recruits privileged advocates, one often finds that they are very effective because of the esteem in which they are held by many people, and because they hold, or have access to, avenues and positions of influence and power which they can exercise on behalf of their protégé.

However, in a certain transcendent sense, such privileged people need their protégé more than the protégés need them, because it is their protégés who lead their souls to personal compassion and morality. While Citizen Advocacy does not exist in order to bridge the chasms within society, nor in order to save the souls of people of the privileged classes who are suffering from a hardening of their hearts, the fact that Citizen Advocacy does contribute to these outcomes is one of its great benefits. Thus, I certainly believe that advocates are right when they say in so many different ways that becoming a citizen advocate has been of great benefit to them--especially moral benefit, and that they should be grateful for it. In fact, the benefit to the advocate may be even bigger than the advocate him/herself realized, especially in the case of citizen advocates who had led a life of privilege, and had previously been cut off from contacts with the lowly and suffering, so that their protégés may indeed have become the instruments for saving their very souls.

Here, I want to chide some of our friends in Britain a bit. Tending to be left-of-center, they sometimes have seemed to imply that they did not want to recruit scum such as conservatives and privileged people as advocates, as if these were either incapable, or undeserving, of such an exalted mission.

In this connection, it bears saying that an advocate's initial motivation seems to be relatively unimportant as long as it is not dishonorable. Many advocates have started out with all sorts of strange notions and misconceptions, but have nevertheless become good advocates and learned a lot. As one advocate and board member (Catanzarite, 1997) put it, "...If you're sometimes whiney, sometimes selfish, and sometimes hypocritical, well then, you just might make an excellent Citizen Advocate!"

I also want to comment on one very important thing we all know advocates do a lot of, but do not say much about, and about which there has not been much written. Namely, they cry a lot--and not only they, but a lot of other people do who are associated with Citizen Advocacy. That there is a lot of crying going on I have observed when advocates told their stories in person rather than in print, and when Citizen Advocacy coordinators told their stories and those of their advocates. There often are also tears simply from hearing or reading a Citizen Advocacy

vignette. On the one hand, the tearfulness of Citizen Advocacy does not really surprise us, but on the other hand, no one in the early Citizen Advocacy literature predicted it.

This crying has to be understood as a wonderful thing, because it is about realities that call for tears, but that so often fail to bring forth tears from a world that in part is unknowing, in part self-centered, uncaring and hardened of heart, and in part just plain too busy. Relatedly, when one hears of all the things that advocates have done for people in terrible straits, one almost cannot bear to think of the life situations of the vast armies of people in equal straits who never had the benefit of a benign human presence, such as that of a citizen advocate, entering their lives.

Tears, grief and sorrow are the appropriate responses to all that. But with so many advocates telling us about all the joy and laughter they shared with their protégés, it is easy to overlook the many tears.

Relatedly, it struck me that you can hardly afford to tell potential advocates the full and whole truth up front. First of all, it would overwhelm them and scare them off; and secondly, it is something they need to learn in a very personal way by a combination of discovery and growth, each advocate in his or her own way and time.

Reading advocate vignettes slowly and thoughtfully for several days on end is like going on a retreat, because it will bring one to ask some very deep questions, and to look at oneself.

People who describe themselves as agnostics or atheists should try this sometime; it should give them much food for thought. There is a persistent undertone--or even overtone--of religious faith in so many vignettes. Even the prominent theme in advocate testimony that one's good deeds come back manifold to one's own benefit--often referred to as a "blessing" by advocates--is really a spiritual one that would not accord well with a materialistic worldview. I could well imagine that Citizen Advocacy might not be very viable in a culture that is thoroughly materialized in its worldview. It is thus ironic that so many people believe strongly that a culture in which people can no longer be motivated to assume unpaid voluntary Citizen Advocacy-like roles is superior to one that they view as riddled with religious superstitions but where these "superstitions" motivate people to act altruistically and unselfishly.

In the light of the many wonderful things that Citizen Advocacy accomplishes, it has long been a mystery to me why anyone who has worked for any length of time in a Citizen Advocacy office, and has had reasonable success making and supporting good matches, would ever want to do any other kind of work instead, and particularly work in formal service agencies, unless one were to do a similar kind of work with volunteers, or were driven by genuine and severe financial hardship.

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