

SUNSHINE COAST
**CITIZEN
ADVOCACY**

Each life you touch
matters,
even if it's only one.

Advocate Independence and Loyalty to the Protege
August 4, 2020 by John Armstrong

Effective advocacy is informed by a set of principles. Citizen Advocacy is no different. Fundamentally, advocates need to be independent. This is especially true when a protégé's life is surrounded by formal paid service requiring an advocate to see themselves as completely independent of those structures.

They will not receive any payment or any kick-back for their advocacy. A citizen advocate will not be receiving course credits for being an advocate or time off with pay from an employer for being an advocate. Each of these would initiate third party inducements to conduct the advocacy a certain way or in a certain direction. The advocacy would likely only last as long as the inducement.

Citizen advocacy is free, remaining independent in order to be effective.

Another nuance to this principle is how the advocate represents and gives voice the protégé's perspective. Other parties can bring formidable impressions reflective of their own expedient interests (in spite of any claims to the contrary) that do not favour the protégé's interests. It will be the citizen advocate who seeks to define the situation uniquely from the protege's perspective. In other words, the advocate is loyal to the protégé.

That is why citizen advocates need to be careful that their association and interactions with staff and service leaders do not compromise their protégé's perspective and their loyalty to the protégé and their interests. They are in their corner and no one else's.



Inside this edition

Advocate Independence and loyalty

Mindsets - John Armstrong..... 2 - 4

Kelly - Disability Advocate (A voice not heard!)6 - 7

Our Citizen Advocacy BBQ 8 - 10

The Trojan Horse Effect: The Client Role and its Impact on Integration12 - 19

Program Information..... 20



Your motivation to help people in
need should not be out of
obligation
Or because you have money
But because they are your
fellow man



Mindsets John Armstrong

Part 1

Social Role Valorisation (SRV) provides citizen advocates a ready reference point for their discernment. SRV alerts us to the potential for people to be treated in culturally alien ways. But what if other people can't or won't see this? It's been said "I'll believe it when I see it", but quite often, even when the contrary is evident, people still refuse to see it. It might be more a case of "I'll see it when I believe it", but of course their mindset ever prevents such occurrence. What is often the barrier to progress for an individual is the fixed mindsets of other key people who control their life. We all have fixed mindsets, things we feel absolutely certain about. If we are wrong, we can suffer the consequences. When the consequences fall on other parties though, such as a protégé, then there is a greater moral responsibility to ensure we see things (as humanly possible) as they really are. But what can get in the way are our (unconscious) mindsets, especially ones built on a fabric of false, invalid or unexamined assumptions. Checking our own assumptions takes some courage. Yet, having others check our assumptions can provide a safeguard against the bravado and arrogance of misplaced certainty. Examining our own assumptions can also strengthen our readiness to defend and protect the interests of a protégé who relies on our ability to speak up convincingly and truthfully about their circumstances.

Part 2

Mindsets have to do with perception. It's hard to take in everything. As we concentrate, especially under stress, we tend to narrow our perception, leaving out what could be crucial information.

For instance, when I first entered a service for people with disabilities, I was overwhelmed with all that was happening; the number of people, its crowdedness, the noise level, the smell, the purposelessness of it all. But with repeated exposure, I narrowed my perception so that it wasn't quite as disturbing; a kind of survival mechanism which perhaps some staff seem to adopt. Of course, not seeing many things relieves the sense of being swamped, but it also

produces "blind spots" to things that could be crucial to a protégé's wellbeing.

But I can't see the blind spots I'm blind to! How do I see something I am no longer looking for? How blatant does something have to be before I take notice of it? (Perhaps you should ask my wife this!) Of course, our mindsets can incorporate blind spots. Some of them we maintain willingly because it is in our interest to never see, or want to see, certain things. We can be willingly blind.

What worked for me was having a framework that helped ensure I didn't miss crucial things. Without it, I was "blind". But armed with my framework, I could now purposely look for what I might otherwise miss. I became more conscious of what my protégé was experiencing and what was taking place in his life that now formed the basis of my advocacy.

What was my framework? The "wounds" of devalued people taught during my orientation informed me how people often experience life (which was shockingly eye-opening!), the negative roles of devalued people which illustrated the roles people were frequently cast into. And with that came the ways roles are communicated, such as through the Settings; the Groupings; the Activities and use of Time; Language and other imagery. Now I have stuff to look for, rather than wondering lost and blind and falling for the idea that its OK to treat people this way!

A central part of an advocates framework is their primary loyalty (identification) with the protégé.

Now I have a wide view for assessing the impact of the overall service, but also a magnifying lens for getting in close. Can I still be blind? You bet, which is why I keep refreshing my framework, otherwise "blindness is just around the corner" with potentially, a terrible impact on my protégé, (and my wife)!

part 3

One of the key benefits of Social Role Valorization (SRV) is that it provides a framework for guiding the efforts of citizen advocates. For instance, a therapist would assess someone in order to remediate that person's delay or deficit based on that assessment. But SRV starts from "the other end", by considering what a person's life could look like if their needs were met, and then

asking what conditions would be necessary to allow that to happen. In other words, it asks us to form a vision with a person about the good things of life they want and need.

But will everyone else see that vision as the advocate and protégé do? A vision is itself a mental orientation that incorporates what is optimistic as well as realistic for a person's life rather than dwelling upon fixated ideas about a person's perceived problems and limitations. In other words, certain mindsets prohibit and/or defeat efforts for achieving the good things of life. Holding an optimistic vision of the future is almost impossible for people of certain fixed mindsets. But growth mindsets are needed if progress is to be made.

But how might the fixed disabling mindsets of other people be approached so as to increase the chances of a person having a better life?

Quite often, one is not dealing with just a shortage of information, that requires "education" to remedy. Its not what we know that changes our mind but how we feel about a given situation that moves us to change. And it is at the level of feeling that an advocate would often have to approach barrier mindsets if they are to make any progress at all.

There are a range of approaches that might be used that encourages and virtually compels a person to feel the necessity for change rather than only being admonished through facts or "the science is clear" type arguments.

It's too large a subject to fully address here, but those interested can reference a wonderful and practical description in an easy-to-read book by Dan & Chip Heath, entitled "Switch. How to make change things when change is hard". You can find it in the link below.

<https://www.penguin.com.au/books/switch-9781847940322>



"No one has ever become poor by giving."
 — Anne Frank, *diary of Anne Frank: the play*



"The best way to not feel hopeless is to get up and do something. Don't wait for good things to happen to you. If you go out and make some good things happen, you will fill the world with hope, you will fill yourself with hope."
 — Barack Obama



"There is no exercise better for the heart than reaching down and lifting people up."
 — John Holmes



"I don't want to live in the kind of world where we don't look out for each other. Not just the people that are close to us, but anybody who needs a helping hand. I can't change the way anybody else thinks, or what they choose to do, but I can do my bit."
 — Charles de lint



"Love is not patronizing and charity isn't about pity, it is about love. Charity and love are the same — with charity you give love, so don't just give money but reach out your hand instead."
 — Mother Teresa



"Non nobis solum nati sumus."
 (Not for ourselves alone are we born.)
 — Marcus Tullius Cicero



(A voice not heard!)

One of South Australia's most prominent disability advocates, Kelly Vincent, says she was left bed-bound for several days while staying in the mental health ward of a major metropolitan hospital.

Key points:

- Former MLC Kelly Vincent presented to hospital in Adelaide with mental health concerns last week.
- Her support agency's policy meant her staff couldn't help with her physical needs, like showering, in the hospital.
- She said there was no lifter, and the hospital's mental health staff felt they could not provide her with physical help.

Advocate and former Member of the South Australian Legislative Council, Kelly Vincent, lives with cerebral palsy, autism, anxiety and depression, along with other mental health diagnoses. She tweeted this week about her stay at the Royal Adelaide Hospital, where she was admitted during a bout of severe anxiety. "With mine [mental health], sometimes it's really good, sometimes really bad, and sometimes it's in the middle," she told ABC Radio Adelaide's Ali Clarke and David Bevan. "Last week, it was heading towards really bad status, so I thought I'd go in and get some help before it got any more out of hand."

Ms Vincent, who uses a wheelchair, was driven to the Royal Adelaide Hospital's emergency department by her support worker, who then helped to explain what was going on to hospital staff. Ms Vincent was then admitted to the hospital's short-stay mental health ward.

"I want to preface this by saying I'm not blaming any one worker — I think the staff at the RAH, on the whole, did the best they could," she told ABC Radio Adelaide.

"Unfortunately, the situation was that my support agency, for whatever reason, has a policy about not allowing workers to assist clients when they're in a hospital stay, which meant my support workers couldn't attend to support me in the morning as they usually would with my physical care needs.

"The mental health staff also felt, at the hospital, that it wasn't their responsibility to provide me with that physical

assistance. "So basically, I ended up spending three days stuck in bed with no shower, not even brushing my teeth or washing my hands." It was only when Ms Vincent's mother visited and helped that she was able to shower.

Mental health 'not helped' by lack of physical support

Ms Vincent said the situation was "pretty tough" and did not help her mental state.

"Obviously, when you're feeling pretty down, and you don't have a great sense of yourself, not having a shower for three days, or not even being able to go for a walk around the ward or outside to get a bit of sunshine, isn't going to help," she said. Ms Vincent said she worried for others who were not like her — "basically a professional advocate" who is verbal and well-versed in how systems work — and the level of support they might receive. "My concern isn't for me, it's for people that don't have those skills or those abilities to regularly articulate what's going wrong," she said.

"Certainly, I've been contacted by a lot of people over social media saying this situation isn't unique.

"It's not what I've been through, it's about the system and changing it for everybody."

Ms Vincent told the ABC she would also be meeting with Health Minister Stephen Wade next week.

<https://www.abc.net.au/news/2021-08-24/kelly-vincent-left-without-showers-for-days-mental-health-stay/100401508>

If you or anyone you know needs help:

Lifeline on 13 11 14
Kids Helpline on 1800 551 800
MensLine Australia on 1300 789 978
Suicide Call Back Service on 1300 659 467
Beyond Blue on 1300 224 636
Headspace on 1800 650 890
ReachOut at au.reachout.com

Our Citizen Advocacy BBQ Botanic Gardens



Our Citizen Advocacy BBQ

Botanic Gardens

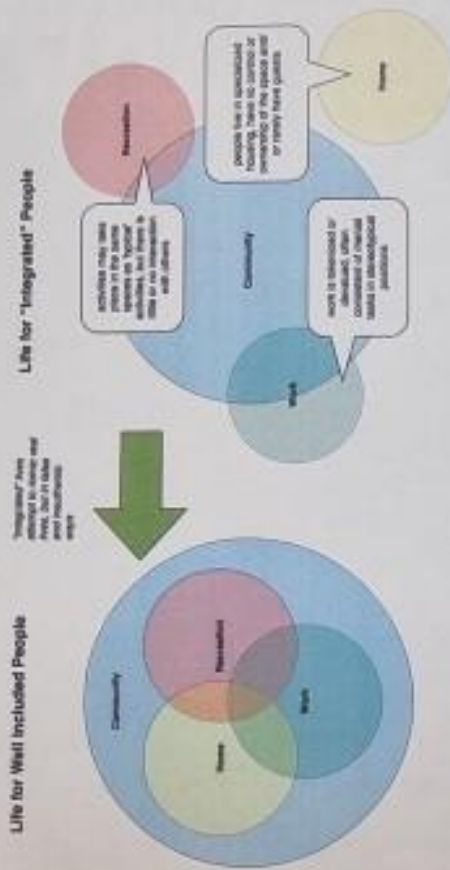


We had over 60 people come to the BBQ and everyone seemed to have had a really lovely day. Thank you for taking the time to come along - and for your great company.

Also a big **THANK YOU** to Paul R. who donated the beautiful plants for the raffle.



The Trojan Horse Effect: The Client Role and its Impact on Integration



Many people are familiar with the idea of the self-fulfilling prophesy, which has also been termed the expectancies construct. This construct asserts that people will fulfil the expectations held about them which will, in turn, further strengthen those expectations. At the core of this dynamic is the notion that people fill a variety of roles, defined as "...a combination of behaviors, functions, relationships, privileges, duties, and responsibilities that is socially defined, is widely understood and recognized within a society, and is characteristic or expected of a person who occupies a particular position within a social system" (Wolfensberger, 1998).

Such roles have a powerful impact on most aspects of our lives including our behavior, the activities we engage in, the people with whom we associate, where we spend time, and so on.

Often, people with disabilities (and other devalued people) fill roles that are largely negative. As Wolfensberger (1972) has written, such roles include non human, object of ridicule, waste object, the object of pity, the burden of charity, the eternal child or child once again, the holy innocent, the sick or diseased organism, and one who is already dead or at least dying. In addition, the role of client has been discussed in the literature as having negative effects on those who hold it, particularly when those people have been devalued by society (Wolfensberger & Thomas, 1994; Lemay, 1999) The role of client, often considered to be benign, actually has powerful negative effects, especially since it has an insidious way of becoming life-defining once a person receives human services. One might consider this the "trojan horse effect" in the sense that the negative consequences of the role are packaged in the benevolent gift of service, only later to be set free to do their damage.

Some of this damage affects efforts to promote social integration. Although the past quarter century has seen tremendous strides in physical integration of people with disabilities, social integration lags far behind (Reidy & Sullivan, 2000). It is only within the last several years that I have become aware of the impact of the client role on social integration. This became clear as I was re-examining a

definition of integration I had been using in my teaching. When teaching about integration, I had used the phrase "affording people the opportunity to participate in all aspects of community life" as the primary definition of integration.

Upon reflection, it became clear that this definition of integration was much too passive. "Affording people... the opportunity to participate sent the message: We'll let you, we won't stop you, but we won't help you either.

In addition, this definition focused more on physical presence, not on relationships between persons. Nor did it adequately describe what contributions could be sought and made by people with disabilities. While physical presence was certainly important, and so was social presence, the deeper challenge seemed to be the process of uncovering a person's unique gifts or potential contributions and then finding a place within the larger community where those could be made manifest. Or, as O'Brien & Lyle (1986) write, "creating a context where a person's identity can emerge."

In order to reflect this deepening understanding of the true intent of integration, I revised my earlier definition to the following: "Integration is the process of helping people fill valued roles that are derived from their unique gifts and talents such that those are recognized and appreciated by other community members."

This definition made an explicit link between valued roles and a person's unique gifts and talents. It attempted to reflect a distinction between generic social roles, such as neighbour, citizen, friend, and personal social roles which allow expression of what makes us unique, of our identity. So the role of artist, or peacemaker, or giver of hospitality are expressions of one's personal social roles. It is not sufficient to merely to fill generic valued roles; there also needs to be an active process of discovering and enhancing each individual's personal social roles.

There is a dramatic shift in emphasis between these two definitions of integration. The first focuses largely on physical presence and can be accomplished by enabling persons with disabilities to co-exist in the community with other citizens, perhaps engaging in some mutual activities. The second focuses on the cultivation of a person's full

identity—which includes both generic and personal social roles, gifts, as well as needs and vulnerabilities. Integration is seen as means toward a much more fundamental goal, that of the realization of each person's full identity through their participation in and contribution to community life.

With this shift in emphasis, a whole new set of concerns and considerations emerges. Rather than only focusing on the activities a person engages in, we need to pay more attention to the **cultivation of relationships as well as opportunities for people's identities to emerge**. When integration is viewed as a process rooted in the identification of each individual's interests, gifts and talents, the powerful obscuring effect of the role of client is revealed. When a person's primary identity is that of a human service client, it becomes far more difficult to envision and enlarge other, more positive and personal, aspects of their identity. In fact "client" is merely a sanitized version of equating a person with their disability, such as when we term someone "a cripple," "a downs baby" and so on.

Although many citizens fill the client role at some points in their lives (e.g., by using lawyers, accountants, doctors and so on), there are key differences (for a more detailed analysis of the differences see Wolfensberger & Thomas, 1994). First, the client role is not life defining for most citizens. It does not supplant other, more positive, roles such as that of productive worker, contributing community member, friend or family member. Second, the client role does not have as many strings attached for most community members. People with disabilities who "accept" the client role pay a huge price in terms of limitations on their autonomy and control. In contrast, other community members who fill the client role retain their ability to choose from various options which may be presented to them while they fill that role, reserving the final option of severing the relationship with one's doctor, lawyer, etc., if the advice is found wanting. Third, the combination of the first two effects leaves people passive and powerless, perpetuating the sense of being a victim. Consequently, one of the key leadership challenges facing proponents of social integration is to assist people with disabilities to fill roles that supersede the role of human service client.

How is the Client Role Shaped?

Woffensberger writes "Expectancies are a core element in the role concept, both in the minds of people who view another person as occupying a certain role, as well as in the mind of the person who fills a role, or is being role-cast. When a person is perceived—at least in a general way—to live up to the expectancies associated with a particular role, then people take for granted that the person is carrying out, or filling, that role" (1998). There are many ways in which these expectancies are communicated such as through the language used, activities, appearance, physical settings, and the other people with whom one associates.

There are a myriad of ways in which the client role is crafted. Any kind of "special service" contributes to the client role. It starts with "early intervention" programs, then proceeds to "special education," "turning twenty-two," "adult services," and so on. While it would be a useful exercise to thoroughly analyze the ways in which the client role is shaped and then communicated, an underlying belief is relevant to the discussion here: That persons with disabilities are not full persons with their own identity. If we believed in the full personhood of people with disabilities, we would have to acknowledge that they possess the whole range of human attributes, including both needs and gifts. As a master identity, the client role severely limits the possibility that someone would be seen as a person with something to contribute. The client role is a form of objectification when applied to people with disabilities: It changes the nature of human interactions, making it one-way, not mutual, removing the possibility of asking the question "Who are we in relation to one another?"

Others have written and taught about this topic for many years. What I am pointing out is not news. Yet, despite the fact that these ideas have been circulating in the field for a long time, the everyday lives of people with disabilities rarely reflect this insight. If anything, at least in the arenas with which I am familiar, we have lost ground as the expansion and institutionalization of formal community services has proceeded.

Possible Effects of the Client Role on Integration

What impact on integration is likely when people with disabilities are seen largely as recipients rather than participants? First, it is likely that people's presence will be merely tolerated rather than welcomed within the settings where they are integrated. Unless people with disabilities (and their supporters) are seen as having something to contribute to a group, a neighbourhood, or a community, they will be met with a lukewarm reception by other community members.

Second, the effort needed to initiate and sustain integration will be enormous and unrelenting, with most of the onus on someone from the "outside" (usually staff) to do the work. If there is no one from the outside, then nothing happens because the welcome is not on the basis of the person with disabilities having anything to offer. People working in supported employment have learned that the best way to help someone get and keep a job is to emphasize the skills a person possesses to perform the job, not focus on tax benefits (the carrot), the Americans With Disabilities Act (the stick) or other "special" incentives to hiring people with disabilities.

Third, people with disabilities themselves do not believe they have anything to offer, or see themselves as like (or perhaps equal to) other people. Such a self-perception can be deeply internalized and be virtually impervious to change even when a person fills what others perceive as valued roles in the community.

Fourth, the people around an individual make no effort to identify and cultivate gifts and instead focus only on needs. At the systemic level, this results in continued expansion of formal services because the assumption is that "clients" need "services," leading to a greater and greater chasm between the "service world" and "community life," also leading to resentment from community members that resources have been siphoned away from their communities, with nothing being given back.

And so we come full circle, with the presence of people with disabilities being merely tolerated in community life because they are seen as making no contribution.

It is difficult to imagine how people with disabilities might live in this day and age without at least some association with formal services, at least in developed countries. Given this reality, what are some strategies to reduce the effects of the client role and expand the number of valued roles a person receiving services might fill, even within the context of formal services? Others have written and taught at great length on this topic (see, for example, Bogdan & Taylor, 1999; O'Brien & Lyle-O'Brien, no date; O'Brien & Mount, 1989; Wolfensberger, 2000) For the purposes of this article, I would like to identify several approaches that seem to have made a difference in practice.

First, a deep consciousness of the deleterious effects of the client role as a life-defining identity seems to be important. This can be accomplished by a variety of educational strategies but the important part is to shake people from complacency. So often, people who have "grown up" in formal services as workers, service recipients, families, and so on become inured to the negative effects or take for granted that the reality they know is the only possible reality. It is especially difficult to envision that people with disabilities could live in the world as full persons when there are few examples of people with disabilities living rich full lives and filling roles that supercede that of client.

Along with a consciousness of the negative effects of the client role is a knowledge of the importance of valued roles and a clear understanding of strategies to help people fill valued roles. Many service workers and even families have a general idea of the importance of valued roles but lack a clear a systematic "roadmap" to enable people to fill those roles. Or, as mentioned earlier, people are focused on the acquisition of generic valued roles instead of tailoring these roles to the particular individual. What may be most effective is an explicit process to identify valued social roles that can be filled by each person and then to strategize about what specific skills a person would need to learn to fill those roles, what other supports would need to be in place, and so on. The clearer and the more personalized the better.

Individualized support practices must be in place, which start with some kind of person-centered planning engaged in by people who care about the person, can envision the possibilities for

the person to use their gifts, and who are willing to make a commitment to helping things happen. Such individualized support envision the possibilities for the person to use their gifts, and who are willing to make a commitment to helping things happen. Such individualized support practices are best accomplished within a flexible organizational structure that is capable of implementing person-centered plans through such mechanisms as flexible staffing, individualized funding, individual or family governed services, and so on. At the very least, the organizational structure needs to be responsive to the individualized nature of this work and not consider group "community outings" or other such activities to be sufficient.

Another very important strategy is the deliberate cultivation of personal relationships with unpaid community people that emphasize the mutuality of the relationship, even if the person with disabilities needs support and assistance to do so. Without this emphasis, efforts to promote community participation will be forever linked to the presence of service workers and be constrained by staffing ratios. In addition, more efforts must be made to identify, cultivate, and support "champions" in all walks of life, whether they be families, service workers, or community people. A recent survey of integration efforts in Western Massachusetts (Reidy & Sullivan, 2000) showed that one of the most powerful preconditions for a person to be integrated was the presence of someone who could serve as a "champion."

The importance of leadership in promoting social integration by those who hold positions determining funding priorities and oversight cannot be over-emphasized. A long term commitment over many years, including the dedication of resources and policies supporting integration is responsible for the progress which has been made and will need to be sustained into the future.

Finally, commitment must be made to participate in broader community improvement efforts, linking the well-being of people with disabilities to that of all community members. This strategy is important if we are ever to get beyond the idea of integration as a "treatment strategy" (O'Brien personal communication, 2000) intended to benefit only the person with disability.

Conclusion

This paper has proposed that integration is a means toward a more

fundamental goal than community presence: the realization of each person's full identity through their participation in and contribution to community life.

By shifting the emphasis, the damaging effects of the client role have, hopefully, been highlighted. Although these ideas have been in circulation in the field for twenty or more years, physical presence and activity-based integration continue to be the standard by which success is measured. In order to make further progress, we have to think very differently about the role of people with disabilities in community life, which has broad implications. As Bogdan & Taylor (1999) write: "Thinking about community for people with developmental disabilities might help us think about it for ourselves. What we want for them—being part of the community—is what we search for... ourselves. To try to solve their problem is to address our own" (p. 3). Perhaps that is one of the gifts that people with disabilities offer to us all.

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One day a man was walking along the beach when he noticed a boy picking something up and gently throwing it into the ocean.

Approaching the boy, he asked, "What are you doing?" The youth replied, "Throwing starfish back into the ocean. The surf is up and the tide is going out.

If I don't throw them back, they'll die." "Son," the man said, "don't you realize there are miles and miles of beach and hundreds of starfish? You can't make a difference!"

After listening politely, the boy bent down, picked up another starfish, and threw it back into the surf. Then, smiling at the man, he said...

"I made a difference for that one."

