



# The Learning Community for Person Centered Practices and Support Development Associates, LLC.

## Supporting Purpose and Meaning Michael Smull<sup>1</sup>

"If I am not for myself, who will be for me? If I am not for others, what am I? And if not now, when?" Rabbi Hillel

If you can't figure out your purpose, find out your passion. For your passion will lead you right into your purpose

T.D. Jakes

We all want to have purpose and meaning in our lives. When it is present we feel fulfilled. Where we find it varies widely and when we don't have it we say we are "adrift". It can be found in our faith, in a cause, in relationships (esp. family), in our work, or even politics. We see it (feel it) in our lives and in the lives of those we admire. The decisions about many aspects of our lives are influenced, often determined by what is needed to support our purpose. Sadly, we don't often look for purpose and meaning (or help support it) in the lives of those who use our services.

The Learning Community for Person Centered Practice's (TLCPCP) definition of "important to" implicitly includes purpose and meaning. We say that what is "important to" are those things that result in feeling satisfied, happy, comforted, and fulfilled. Among those, feeling fulfilled only occurs when purpose and meaning are present. However, the implicit inclusion of purpose and meaning is not sufficient. Helping those we support find purpose and meaning is now rare but must become routine. Where it is present it is often not recognized, and changes can be made in the lives of people that take away the purpose and meaning that was present.

#### It's complicated

What gives us purpose and meaning is complicated and more so for people who have not had the opportunities needed to find it nor the control needed to keep it. Fulfilled is more than the happy we demonstrate when somebody gives us something or does something for us. In studies done in a variety of settings "happiness was related more to being a taker rather than a giver, whereas meaning was related

<sup>&</sup>lt;sup>1</sup> While I am listed as the author and I am solely responsible for the content, others contributed stories and feedback. Lori Hauge started this work by asking why TLCPCP did not make the importance of purpose meaning clear in our work. Other contributors include: Laura Buckner, Nolda Ware, and Alison Whyte. Thanks also go to Claudia Bolton, who reminded me to look at the work of Martin Seligman.

more to being a giver than a taker."<sup>2</sup> Inherent in this frame is the idea that each of us chooses whether or not we want to be a "taker" or a "giver". Those who use services are not choosing to be "takers". They are more accurately described as "receivers", rather than "takers". Where they are givers, it is largely within relationships and is often not recognized. Where opportunities to give are developed they rarely have control of the opportunity. Still there is a key takeaway: Without opportunities to be a "giver" purpose and meaning is out of reach for most.

In other work, a group of psychologists (whose thought leader is Martin Seligman) say it is helpful to think of a hierarchy of happiness<sup>3</sup>:

- a Pleasant Life,
- an Engaged Life, and
- a Meaningful Life

Seligman goes into a more detailed vision with what he refers to as "well-being" whose elements make up the acronym PERMA<sup>4</sup> –

- positive emotion,
- engagement,
- relationships,
- meaning, and
- accomplishment

In the person-centered thinking training we use the "Service Life to Community Life Continuum" arrow below to talk about how the goal for all of us is "community life" and that we often settle for a "good paid life" for those who use our services. In the hierarchy of happiness, a good paid life would be the equivalent of a "pleasant life". What we call community life would take us to an "engaged life" but may leave out a "meaningful life". Our usual definition of "community life" in the context of PERMA suggests that you have positive emotion, engagement, and relationships but there is no focus on meaning and

<sup>2</sup> Scott Barry Kaufman <a href="https://heleo.com/a-cognitive-psychologist-investigates-the-science-of-happiness-and-fulfillment/9027/">https://heleo.com/a-cognitive-psychologist-investigates-the-science-of-happiness-and-fulfillment/9027/</a>

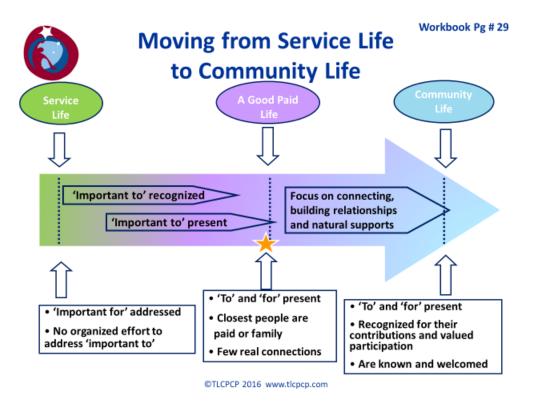
Also see Give and Take by Adam Grant and/or watch his videos

<sup>3</sup> www.derekstockley.com.au/newsletters-06/085-happiness-types.html

<sup>4</sup> For a quick review go to <a href="https://www.habitsforwellbeing.com/perma-a-well-being-theory-by-martin-seligman/">https://www.habitsforwellbeing.com/perma-a-well-being-theory-by-martin-seligman/</a>

For more detail: <u>Flourish: A Visionary New Understanding of Happiness and Well-being</u> by Martin E. P. Seligman

accomplishment. Our vision of community life should include all the elements of PERMA. Every person we support should have the opportunities and support needed to have a meaningful life.



As we look at these frames for thinking about support it is helpful to note that we are all "receivers" and "givers". We all need support (and hopefully receive it). Those who use services need additional support and in their roles as service users, are "receivers". But receiving supports does not preclude being a giver. The effects of polio meant that Franklin Roosevelt needed the support that a pre-ADA environment required, but that did not stop him from giving when the country was in dire need. Part of what we need to address is an assumption that if you are receiving support you are not expected to be (or not seen as capable of being) a giver.

Too often we seek and settle for a "pleasant life" for those who receive services even though it is not enough for ourselves. A pleasant life should be seen as a foundational goal for those who develop and implement plans. Therefore, learning what is needed for a pleasant life is often where we need to start, but it is not an OK place to stop. As some of the following stories indicate, gong moving up the hierarchy from pleasant to engaged to meaningful is not necessarily sequential. Successful efforts can have an impact on more than one component of PERMA at a time.

The responsibility for seeking and supporting purpose and meaning rests with all of those who work in the system that provides services and supports. It not only lies with those who develop plans but includes

policy makers, managers, and those who provide direct support. Do the system's policies require that we help people seek purpose and meaning? Do mangers structure their services so that purpose and meaning are sought and supported? Direct support professionals are by definition "givers". Are they expected to look for giving among those who receive services? Do they recognize it? Do they support it? Do they see finding and supporting purpose and meaning as part of their roles? The answers to all these questions needs to be yes,

#### When we are looking at change in someone's life are we taking meaning and purpose into account?

In person centered thinking training we say: "what you see depends on what you are looking for". For many people, when we look for purpose and meaning the answer is right before us. When we miss it or don't take it into account the result can be disastrous. Decades ago I was running an agency that was asked to bring people from institutions to community settings. As a part of those efforts Larry moved into a house with Jacob. Larry, who was in his fifties, looked out for Jacob and helped support him. Jacob was in his seventies and needed support to stay safe and had no skills (or interest) in things like cooking or cleaning. We ruminated in endless meetings over whether we should "allow" Larry to provide support that staff would otherwise provide. We were also concerned that Jacob was not being as independent as his "potential" suggested. Was Jacob taking advantage of Larry? As far as we could tell both men enjoyed their relationship. What we didn't see was that supporting Jacob gave Larry meaning and purpose. We did nothing about this for a year and then in Larry's annual assessment it was noted that he had adjusted well to the community, had demonstrated significant growth in independent living skills, and there was no sign of the fire setting that had caused him to be admitted to the institution. We were proud of Larry and of our efforts. But his growth meant that, under our funding rules, we could not justify Larry living in a home that had 24 hour a day supervision. However, Jacob still met the criteria for 24 hour support. We congratulated Larry and moved him to his own apartment with drop in support. He no longer lived with Jacob and he had no way to provide Jacob with the support that he had been routinely giving. A couple of weeks later he told us how he felt by setting a fire. No one was hurt, and it was quickly extinguished by the fire department. But we lost control over where he lived, as he was recommitted to the institution. We missed the healing power of purpose and meaning and Larry paid the price for our mistake.

Theresa moved into a nursing home. Her husband had died, and her children were concerned that she was no longer able to address her needs without support. They said to her: "Mom, you have spent your life caring for us and your husband. It is time that you enjoyed having others care for you." Theresa was touched by their love but became depressed. Caring for others was what gave her purpose and meaning and now it was gone. The staff of the nursing home had just been trained in person centered thinking and rather than give Theresa antidepressants they asked if she would be willing to care for the birds that were in the common areas. They asked if she would be willing to deliver their newsletter and use that as an opportunity to chat with residents who were lonely. Theresa said yes, started her new tasks, and her depression lifted.

#### Purpose and meaning: opportunities missed

Sharon lives in a group home with seven other people and occasionally an 8th who stays there for a shorter respite period. On some days, she attends a day habilitation program and on other days she goes to a sheltered workshop (which she just calls, "the workshop"). Sharon is a fairly "happy-go-lucky" person who loves to talk to people, enjoys taking care of her fish, and has a gift for style and decoration. Sharon likes most of the people she lives with, but there are a couple housemates that she feels interfere with the way she wants to do things. She has dealt with this by trying as much as possible to avoid them and only interact with the people she likes. Sharon enjoys going to her day program, especially when they have "dog therapy" because she loves animals. She calls herself a "dog whisperer." She doesn't always like going to the workshop because she sometimes has to do tasks that she does not find interesting. She especially hates working with gaskets and will complain when the workshop has these contracts. On these days, she'll often end up telling staff she doesn't feel well so she can take a nap. Staff at the workshop have fallen into the "readiness trap", saying that if she can't show productivity at workshop, then she's not ready for community employment.

Sharon has a really good friend named Mary that she hangs out with at the day program and at the workshop. Mary doesn't communicate with words and Sharon feels that she has a special connection with her and can understand her needs and wants. Mary will smile and light up when she sees Sharon coming and they will have entire conversations together. Sharon often alerts staff when Mary needs something and she sees herself as Mary's personal communicator. Whenever Sharon is "allowed" to have a guest at her home, she always invites Mary and they have a great time together. This is not the first time that Sharon has gravitated toward someone like Mary. Sharon loves to help people. She is committed to making sure people are heard, so she does what she can to make sure people who don't communicate with words still have a voice. Staff have often commented that Sharon and Mary have a great friendship and sometimes will specifically request for Sharon to come help if Mary is having a bad day.

The staff at the workshop are stuck in old ways of thinking. They are in a "readiness trap" and not thinking of employment. They are not looking at what is working and not working for Sharon at the workshop. They are not exploring whether her perception of herself as "dog whisperer" has the potential to become more and could lead to paid or volunteer work with purpose and meaning. Sharon is living in a setting that she doesn't like. Sharon's commitment to Mary is something to explore both from the perspective of the potential of alternative living arrangements and the question of whether her gift with Mary would generalize to others (and give purpose and meaning).

We also see that having purpose and meaning in one part of your life can be an excuse for not resolving issues in other parts of your life. In this odd way of thinking, having something going well in one part of your life justifies not acting on areas that are not going well. Jim is seeking to complete his training in cosmetology and sees his efforts as opening the door for others who have disability issues. His "team" recognizes and applauds his goal but uses it as an excuse for not acting on his clear dislike of a housemate who has significant challenging behaviors.

#### The intersection of fulfilled and happy

Andrew takes care of the property of the church he belongs to. It's a huge piece of property. Years ago the church paid a lawn service to do it and it was expensive. The church is relatively small in members and has limited funds. Andrew (who operates his own lawn service) heard the conversations about the cost and offered to do it without pay. He considers it his "donation" to the church and takes great pride in the work; when the offering plate comes by he whispers: "I have already donated with my mowing!" He is thrilled when someone comments on his work, or thanks him for it.

Recently the priest approached Andrew's mom and dad and told them he had a difficult question. "Was the church taking advantage of Andrew by having him do the property maintenance for free?" Andrew's parents gave an emphatic no and went on to explain the purpose and meaning Andrew finds in doing that work.

Every year, shortly after Thanksgiving, Andrew wears a Santa hat all day, every day. He wears the hat to work, to the grocery store, to church. When asked why he wears it he says it helps "spread the Christmas spirit", "makes people smile", "makes people happy and cheerful". Some staff and even family members have suggested that the Santa hat is "inappropriate" and encourage Andrew to leave the hat at home, but they are missing the purpose and meaning Andrew finds in the outcomes he sees when he wears the Santa hat. Over time family members and work colleagues began recognizing the social opportunities the Santa hat provides Andrew. People smile, some comment on his hat, and suddenly a conversation is taking place.

#### The challenge of separating supporting purpose and meaning and exploitation

Larry's, Sharon's, and Andrew's stories raise the question of exploitation. When someone is engaged in an activity that could be paid, should they be paid? The answer for Andrew is straight forward, Andrew is making an informed choice. He sees himself as a valued and contributing member of his congregation. Should Larry's services have been arranged so that he could continue to support Jacob? The answer is clearly yes, but how should we have addressed the issue that Larry's efforts displace staff time and responsibilities? Should Larry be paid for the support he gives to Jacob? Should Sharon be paid for her support of Mary? There is a strong argument to be made that Sharon and Larry are providing a valued service and should be paid for it. But there is another, equally strong argument to be made that their efforts are at the core of the relationships that they have. We should support them in their efforts, but not turn them into jobs. We can also look to see if Larry or Sharon would like to consider jobs that used their gifts in providing support to others.

#### Discovering purpose by looking for passion

We can find purpose by discovering that we have a passion for something. But how do we help when passion hasn't been found? One response is to help people volunteer. Being a volunteer means that you are giving, making a contribution. While volunteer opportunities are one way to help people discover a passion that leads to purpose, there are caveats. Are those engaging in the volunteer activities doing it because they want to or is it because someone else wants them to? Are people going thru the motions without passion? Is it part of a program rather than a thoughtful part of discovery? In a revealing meeting Nolda Ware asked a group of people why they volunteered. Some of the responses follow -

- Because staff says I should.
- Because mom says I should.
- It's on the program schedule.
- Because I have to.
- Fills up my day gives me something to do.
- So I will go to heaven.
- I don't know.
- It looks good on my resume can help me get a job.
- It makes me feel good because I am helping people.
- To give back to help out my community.
- It makes the world a better place and I want the world to be a better place.
- Because I love animals so much and want to make sure they are ok.
- Everybody should pitch in then life will be better for everyone.

The responses tell us the of the danger of programs that reflect **power over** thinking. Most of the responses reflect the coercive nature of programs. Volunteering is a way to give but it should also give us meaning. It should be done "with" the person and not "to" the person. Several of the responses suggest that the participants have found some meaning in the effort. But unless it is seen as part of discovery process with intentional efforts to document the learning, the learning may not lead to the outcomes we are seeking. Where meaning is present do we recognize its importance and potential? Do we spend time with the person to see if they want to build on it? If It just something on the schedule, it is easily lost when program circumstances change.

#### The role of volunteer programs

A well-done volunteer program can help people discover their passion and find purpose and meaning. It can also be a way to sustain purpose and meaning. However, a volunteer program can reflect "power over" rather than "power with". If "volunteering" is on the schedule and you are expected to do it, you are not really a volunteer. The Cambridge English dictionary defines volunteer as "a person who does something, especially helping other people, willingly and without being forced or paid to do it". Where volunteering is part of a discovery process there also needs to be structured ways to learn from each

experience. Teaching staff (and the person) to use the learning log or other everyday learning skills is critical. It needs to be a process where the person has control. Where trying something new requires encouragement we need to remember that there is a difference between encouraged and coerced.

There are programs that rotate work and volunteer opportunities. Having a variety of experiences provides opportunities for learning and makes sense for some people. But when the person finds purpose and meaning in their volunteer work, but we shouldn't just "rotate" the person out of the work. Volunteer work is also frequently used bridge to paid work. If purpose and meaning is present in the volunteer work, we should ensure that it will continue to be present in the paid position. If it is not recognized or its importance is not seen, it can be casually destroyed.

Where volunteer efforts have led to finding purpose and meaning there are some final questions:

- If the work provides purpose and meaning and is unpaid does the person want it to be paid?
- If the work provides purpose and meaning and is part time, would the person like it to be full time?
- If the work provides purpose and meaning and is full time, would the person like it to be part time?

#### Happiness, status, passion and purpose

Feelings of accomplishment and having others appreciate your work often underlie feeling fulfilled. Chris was well liked but was also seen as someone without motivation; someone who saw no reason to work. As his team got together to consider his move to his own apartment they asked Chris, his Mom, and others.

- What does Chris do that makes him happiest? And Why?
- Who is around him when he is really happy? And why?
- What seems to motivate and inspire him? And why?
- What gives meaning to his day? And why?

These were questions that Chris struggled with, so they relied on some of Mom's answers -

- He seems happiest when he is helping people out.
  - Being around people who are grateful for his help say thank you.
  - Being around people that recognize what he has to offer.
  - Doing something people see as "important."
  - Being given responsibilities and making a difference to someone or something.
- Being around people who treat him as an equal.
  - Opportunities to have a "leader" role.
  - o Being places where people know him and like him.

- That he is not defined by and connected to his label of a person who has a developmental disability.
- When he is not committed to a set schedule has lots of flexibility.
- Moving, being active not sitting in one place.
- Doing ordinary things in interesting places on his terms-and connected to the things he loves.

The team thought about the answers and then talked to the property manager to see if there were any job openings at the apartment building for Chris. There was one. He was hired as the apartment custodian. This is an important job as he keeps the building clean and safe; helps the tenants when needed; and reports to the property manager about any issues or concerns. Now everyone knows Chris; everyone appreciates him and what he does. People go to him for help, he knows his neighbors and made some friends. By thinking about happy, status, and passion, those who support Chris helped him find a job where he found purpose and meaning.

#### Purpose and meaning and dreams

When we look for purpose and meaning are we asking about dreams with different words? Yes and no. Dreams, as we ask about them, are about achieving personal goals. They may be about purpose and meaning or they may represent something more concrete. Having a job with a living wage is a dream for many but it may or may not give purpose and meaning. If part of the dream is to make enough money be able to support my family (or for one young man, to support his mother) then there is purpose and meaning, there is being fulfilled. Dreams that have the element of giving to others are likely to give purpose and meaning when they are acted on.

#### Purpose and Meaning as another question on a form

If listening for purpose and meaning becomes an expectation, how can we avoid the perversions? How can we avoid it being a token effort that reflects compliance rather than commitment. If it is seen as just another question on a form, there is also the temptation to invent something simply because a question is being asked and an answer is expected.

If it is a question to be answered in a larger assessment process, those completing it may settle for the superficial responses where one or more of 3 typical answers is given as a single word or short phrase (i.e. family, faith, or caring for others). While the answers may be true, they do not have enough detail to help us take actions to support or to further develop them. As a part of helping those who are paid to support see the importance of purpose and meaning I ask them to tell me what purpose and meaning is for them. The most common answer is one word, family. When asked to expand, the answers are about contributing financially, protecting, or teaching values. When asked to give an example or explain more fully there is still more detail and you begin to see how you would support the person (if support were needed). Those who are developing plans need to be competent in discovery skills and processes. They need to use these skills to develop the detail necessary to be able to support the person in

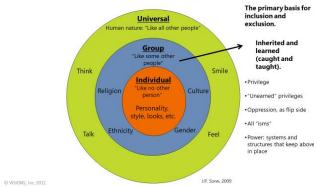
maintaining what gives them purpose and meaning. Where purpose and meaning is absent they need to use the skills to give those who implement a place to start.

Where finding purpose and meaning is an expectation of the system, it will be seen as needing to be a goal that achievable and measurable. Given the often-sad state of goal writing this could become something that says, "Sara will have a volunteer opportunity of her choosing weekly" and be seen as done. Simply requiring that purpose and meaning is addressed is a version of "change by memo". Effectively addressing purpose and meaning requires understanding of what it is and appreciation of its importance.

#### Purpose, meaning, and culture

Purpose and meaning has a context, it occurs within the culture that the person lives in. When looking to see if purpose and meaning is present (or seeking to help the person find it) we need to know what is valued within the person's culture. Where people are living at home, we need to learn what is valued in the context of the family and within the person's community. We need to help find and/or support desired opportunities to give (as well as receive. As the graphic below suggests, while we need to look at how the family sees purpose and meaning, we need to include what is valued It by all of the communities in which the person spends time (or could be part of) and should consider issues of gender and ethnicity.

### **Self Focus: Multiple Identities**



#### **Moving forward**

As supporting purpose and meaning moves toward being a central part of our responsibility in planning with and supporting people, there will be push back. Some of it will come from people who simply haven't considered its importance. Some will be from those who already feel overwhelmed and resist having one more goal. Finally, there will be those who feel that an intellectual disability, or issues associated with aging, or being in recovery from a significant behavioral health issue, precludes having

purpose and meaning. Part of managing this resistance is to have more shared stories. Stories about the purpose and meaning present in people's lives now and the journeys taken to find it. We need shared stories that will counter the inevitable objections that begin with "I see how it works for 'those people' but I work with people who have ..." We need to change the negative assumptions. We need to show that when purpose and meaning is absent, it is not about the nature of the disability but is about the absence of a discovery process focused on learning that leads to finding what the person loves, what their passion is. It is about the absence of opportunities that uncover the passion is underneath purpose and meaning. It is having supports needed sustain purpose and meaning once it is present. Just as seeking and holding purpose and meaning is a central part of our lives, it is a central part of the lives of those we support.

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