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Kontakt / Contact:

penocs

DIPF | Leibniz-Institut für Bildungsforschung und Bildungsinformation Informationszentrum (IZ) Bildung

E-Mail: pedocs@dipf.de Internet: www.pedocs.de



Beth Gallagher and Kirk Hinkleman

Flipping the Script: Intentional Teaming through Awareness-Based Collective Action

Abstract

Life Works Supported Living Services, the organization the authors co-direct in San Diego, CA, has been thinking of questions about what real Inclusion looks like for people experiencing developmental disabilities since its inception in 2004. The thoughts, philosophies and practices presented in this chapter are drawn from their years of experience in the field of disability and Inclusion. It leans on and embraces works of thought leaders in the field like John O'Brien and Beth Mount and also explores pedagogies from outside this particular niche field of practice, especially Otto Scharmer and the Presencing Institute's work on Theory U.

Life Works Supported Living Services, die Organisation in San Diego, Kalifornien, welche die beiden Autor*innen gemeinsam leiten, hat sich seit ihrer Gründung im Jahr 2004 mit der Frage beschäftigt, wie echte Inklusion für Menschen mit Entwicklungsbeeinträchtigungen aussehen kann. Die Gedanken, Philosophien und Praktiken, die in diesem Kapitel vorgestellt werden, stammen aus ihrer langjährigen Tätigkeiten im Bereich der Inklusionsorientierten Arbeit mit Menschen mit Behinderungen. Sie ist inspiriert durch Vordenker*innen wie John O'Brien und Beth Mount. Es betrachtet auch Ansätze außerhalb dieses Nischenbereichs, und dabei insbesondere die Arbeiten von Otto Scharmer zur Theorie U.

1 Introduction

People experiencing developmental disabilities trying to live a 'real life', trying to breathe under the vice and grip of services and a system supposedly designed to support someone to live said 'real life', find themselves lacking the oxygen needed to reach a desired future. This is heartbreaking. People experiencing developmental disabilities live their lives in segregation and isolation. In 2021, people still find themselves marginalized and voiceless, even in the midst of living 'in' the community surrounded by people who are 'listening' to them and who are largely paid to do so. When will we hold the system accountable for its actions? When will we break

the cycle of looking disingenuously into someone's future? When will we stop being informed by someone's past typically represented by a daunting, oversized paper file filled with reports from past decades, special incidents and a trough of content about the person's deficits? The answer is Now. It starts with our awareness and presence with our current reality. We slow down. We lean into purpose driven practices. We break the cycle and slow down long enough to deeply listen to those we surround ourselves with. We connect on the level of the heart and level the field to a human connection, honoring the shared humanity permeating our relationships. This sacred energy is healing. How do we honor this human connection, holding it as the most important element of our work, in the midst of the omnipresent demands placed on us by the System? What cultural shifts does the organization need to attend to and what are the practices that keep us as individuals disciplined and grounded in our mission of lasting change?

2 Intentional Teaming: Designing and cultivating teams of custom designed support

Intentional Teaming is a culture that is evolving continuously. When we gathered the information for our book, *Intentional Teaming: Shifting Organizational Culture* published in 2012, we knew the material would likely be obsolete before the ink was dry. Teams are never done developing and sprouting. At the same time, we are never done pruning what needs to be shed or what is not working. The ability to pivot and pursue what comes next has long been a gift of the teams at Life Works.

Life Works provides customized, person-centered support to individuals experiencing developmental disabilities, wanting to live real lives in homes of their own and in communities of their choosing. Life Works creates teams of people surrounding an individual being served, meaning we hire and cultivate groups of people around a shared vision for a person's life which is co-created with a person's circle of support. Collectively we hold onto this shared vision and use it as the driving energy, or compass, for all we do with people. We believe in creating space for direct support professionals (team members) to form relationships with the people they support. Life Works does not hire for Life Works. We hire people to be matched with the person receiving services and supports. Life Works is composed of a group of Teams: Team Tim, Team Joaquin, Team Tami, etc. We consider Life Works to be many different micro-organizations, all held together with the values of inclusion along with theories and frameworks we'll talk more about in the coming pages of this chapter. We (Beth, Kirk and Life Works as a whole) have the ability to ask ourselves fundamental questions about whether or not people are thriving, consistently.

dogma, requires visualization and forethought. We need to be able to work cohesively and in a predictive nature to understand what will help us prevail under duress. How will each team handle coercion? This is why we have created a system of healthy micro-businesses rather than one large ever changing agency. While there is an overarching policy structure within Life Works itself, each team is managed a little differently and with a slightly unique approach drawn from the gifts of that team, the person supported and that of the coordinator. This has proven invaluable each time our system has been tested. Whether we were faced with catastrophic medical issues on our management team or when the COVID-19 pandemic hit in 2020, Intentional Teaming and the theme of sustainability was a Champion we could lean on.

Remember when the pandemic rushed upon us and we stood still for a moment? It was as if we needed a jump start to get out of our own way. It was as if we were chained to the floor and we could not move forward. Something was stopping normal everyday propulsion. One day I, Beth, found myself in a ZOOM meeting with leaders from all around the world pondering the events of the previous few months. It was a gathering of nearly 1000 people from all types of industry, all walks of life, all forms of helping. It was a gathering of the Presencing Institute out of MIT in Boston. led by Otto Scharmer. Thoughts were being shared, poems were being read and ideas were being formulated. Breakout rooms of 4-5 people were created at one point and posed with the question, "share what is helping you make it through these times". A woman in my room was discussing her current situation: She was from Chile and she spoke exuberantly for about 3-4 minutes. What she said at the end of her allotted time, made me stop in my tracks. She said, "We MUST step forward and do something: and not let the PERFECT be the enemy of the GOOD!" YES...this is exactly what leaders in our system were doing. We were waiting for ideas and solutions to be perfect. We were a failure to launch because we could not see the final results as seamless resolutions. Once I heard that statement, it rocked me right into place. We must prototype like we always have: try out an idea and keep testing it out. If it isn't quite right, adjust, pivot and keep going. "The Next Best Question" is the 5th chapter in Intentional Teaming: Shifting Organizational Culture. Had that chapter been written in 2021, "we MUST step forward and do something: and not let the PERFECT be the enemy of the GOOD!" would have been woven deeply into that chapter. Curiosity and perseverance go hand in hand. It is entirely about digging deep and not allowing perfection to interrupt drive. Just as the lives of people do not stand still, neither does the planning around how we support those individuals.

3 Relationships

We are not caretakers. We are people who support people to make connections. Caretakers work to complete a shift or a finite list of tasks. Conversely, community builders work to develop the capacity of others. We help people create compe-

tence and aptitude that will serve them well when they venture out into the vast wide world. We spend a disproportionate amount of our time and energy helping individuals to understand that their words (whether spoken, typed, written, texted, through ASL or in whatever fashion) are powerful. The words that come from the individuals we support are heard, listened to, and honored. The intention is that over time, being listened to will increase confidence. In addition, it will erode the power gap between people with disabilities and the rest of the population.

We found that we are frequently in conflict with the status quo with regard to other organizational theories about relationships. The traditional rhetoric surrounding the topic of relationship is that the people providing support and the people receiving support are not compatible. It has long been said that the two parties should not commingle. A friendship should never be condoned between the two parties as one of the parties is paid. Words such as inappropriate, incongruent, unacceptable or immoral, are all used to form a conclusion that the nature of these relationships lead to improprieties. We emphatically disagree. Intentional Teaming and giftedness lead us to true relationships. We believe that genuine, robust and enduring support cannot happen without a substantial and growing relationship. Support can be provided but it would certainly be deficient. We strongly believe the stronger the relationship between the two people, the safer the person experiencing disability is. We do believe in appropriate boundaries while promoting authentic and veritable relationships that develop over time.

Our professionalism can sometimes create a clinical situation out of something that is as simple as an introduction between two people. Community building is not "rocket science". It does require some grace and courage to take a risk. However, it is not so complicated that it involves someone with a college degree or significant schooling in order to be successful.

Unfortunately, our system has designated so much oversight and regulation that spontaneity has all but been bled from the flow of a single day. It is incumbent upon us to stave off the catapulting thrust of a growing list of procedures burdening direct support professionals. We must resist this wherever it makes sense. Wherever it thwarts the lifestyle of community living, we must stand up and push back on the rules that don't make a bit of sense.

4 Giftedness: Liberty Plan and the unique gifts of each person

"A gift is anything you are, have, or do, which creates an opportunity for you to interact with someone else. Under favorable circumstances such interactions can then be built into sustainable relationships and social and economic opportunities"

Judith Snow, Visionary, Consultant, Trainer and Artist

For too long, human services systems have been mired in addressing skill deficits. The system insists we ensure a person can brush their teeth with the fewest prompts

possible before his next annual review. We pay careful attention that a person can spread butter on toast with the least support possible. If brushing teeth and buttering toast are truly the life goals of the person receiving services, then we should focus on these goals diligently. However, this is hardly the case. Which would you pick, developing friendships with people by hosting a game night at home with hors d'oeuvres and karaoke, or brushing teeth and buttering toast? The choice is obvious. When you look at it closely, it seems silly. We have hung onto this approach for decades because it has always been done that way. It is measurable so we measure.

What would it take for an organization to slow down long enough to feel, hear, and see what is going on around it? It really takes co-sensing the surroundings in all levels of the organization. What do you *feel* when you walk into the home of someone you support?

What do you *hear* when you initiate a stakeholder interview with a team member? What do you *see* as you walk through a community with someone receiving services? Co-sensing is the real person-centered planning that needs to take place. It is not the elaborate template on the wall with colorful chalk and marker icons created in vibrant team gatherings. Those are absolutely necessary and generate such rich and imaginative ideas that are multi-faceted. However, they are isolated. This 'template' creates a single plan that is then put into place. The hope is for any person that a team will follow through with the plan and not let it die on a shelf. True person centered planning must happen at all times. An agency, a circle of support or a team must infuse the ideas and themes of person centered planning into all levels of the organization: Finance, Human Resources, Boards of Directors, Training, Web Development and so on.

Person Centered Planning is not an event, it is a culture.

Wherever there is human interaction, there can be an influence of person centeredness. Person Centered Planning is not an event, it is a culture. It should affect how hiring is done, how budgeting is done, how the website is built, how the board of directors is designed, how training is carried out, and also who has influence on all of those events. The persuasion of person centered planning should not be drowned out, it should grow over time. The stronger the presence in an organization, the more robust the culture. Person centered planning must have persuasion on all facets of an organization.

5 Purpose Driven Practices: Honoring the relationship between patterns and practices leading to a cycle-breaking awareness

We find ourselves trapped in a cycle. The cycle goes something like this: we think about our futures, play out scenarios, crunch numbers and ultimately begin to figure out all the reasons why it will be difficult to get to these futures, given how

our pasts have gone. Scenarios, numbers and doubts. This cycle is amplified for people experiencing developmental disabilities trying to live a 'real life', trying to breathe under the vice and grip of the services and a system supposedly designed to support someone to live a 'real life'. To say this is a vicious cycle, would not give the credence deserved. People experiencing developmental disabilities live lives of segregation and isolation.

In 2021, people find themselves marginalized and voiceless, even in the midst of living 'in' the community surrounded by people who are 'listening' to them, most of whom are paid to do so. Professionals. Perhaps we find an opportunity here to point out the cycle of 'staffing' paid employees to be with service users. When we boil it down, this is the true existence of large numbers of people living under the umbrella of services, 'protected' from the threat of real precipitation. For us, it's more like 'precluded' from precipitation that could yield organic growth. A large American corporation genetically modified seeds and strategically spread them throughout the agricultural system, overriding the capacity for authentic seeds to grow and to thrive. Much like this process, the service system has genetically modified relationships in the labeling of roles, Direct Support Professional and Service User. What we must be aware of, is that this reality is not a real relationship, it is a transactional relationship. When this transactional energy is present, upheld by pervasive philosophies imposed by organizations such as professional distance, the space for the emergence of real relationships becomes smaller and smaller.

We find ourselves sucked into a powerful vortex of staffing, schedule covering, medication delivering and report writing. When we get to the next meeting, we look at the reports we've written to inform the one we will write for the coming year of someone's life, which if we fast forward, will look much like the previous year lived. A life designed to serve the system and its mechanical regulations that fails to help, in any way, to actualize the real life the person desires to live under the weight of all these machinations.

What this back and forward cycle neglects, is the present moment. At this moment, right now, we become aware of what is happening. From this awareness, we have choice. We can choose to continue to lean into theory and practice perpetuating segregation and isolation, or, we slow down and be with our awareness of what is happening right in front of us.

Cory Muscara¹ writes: "From awareness, comes our ability to see what is happening, and choose not to become it." Let us choose not to perpetuate the devaluing of humans and rise up with an energy of presence and thoughtful action.

At the core of all purpose-driven practices is that of listening. Listening with *Open minds, Open hearts, Open wills,* as Otto Scharmer (2018) writes about in his book "The Essentials of Theory U: Core Principles and Applications" and teaches in cours-

¹ See www.corymuscara.com

es at MIT and through the Presencing Institute. Scharmer categorizes listening into 4 Levels of Listening. We, as an organization, do our best to be mindful of these levels and try our best to put the theory into practice on a daily basis. Our breakdown from his teaching around Levels of Listening and how we implement them, is as follows:

Level 1 Downloading, Scharmer identifies, is our default mechanism. It's the level we find ourselves in without attention to what is happening. Without mindful presence, we listen with closed minds, reconfirming old opinions and judgments. In the context of the service system, we do this by accepting what is written about people in the files we receive as an introduction to people. We've alluded to the nature of these files, the damage they carry with them about people and the narratives of what is possible or not, simply because of what years of 'professionals' have written. The surface-level of listening, driving the content written to supposedly design a person's life (services) on their behalf, fails to tap into the depth of humanity needed in guiding a person toward a purposeful life. In the context of day-to-day conversations with others in the community, we're just waiting for our turn to talk, not really listening to the content and energy behind the words another speaks. Instead we wait for physical cues in the form of breaks and stops to interject our 'armed and ready' opinions and judgments about the person or the situation. For us to it is paramount to break the cycle of perpetuating the isolation and segregation of people with disabilities, an awareness of the walls Level 1 Listening traps us in. Remember Cory Muscara, who said first awareness, then the choice not to become what we see happening.

Level 2 Factual is where we begin to notice differences between our preexisting notions of people and what is actually being said and understood. We 'listen with Open Minds', present to the other person if only observational, we set aside what we came to the conversation holding onto. We need to let go of, as Scharmer puts it, the 'Voice of Judgment'. This affords us, as supporters of people experiencing disability, the space needed to observe and harvest the important elements of a person's story as it is presently being told. We listen with an open mind to another human being and the telling of their story, thus, 'disconfirming old data while confirming new data with a sense of curiosity'. For us, as an organization, we turn this into a practice.

The typical sequence of events when someone is referred to us by our governing agency here in the state of California, is to receive what is called a "collateral packet", a label given by the Department of Developmental Services. Let's stop and think about that label. Webster defines collateral as "informational materials used in selling a product or service to a prospective customer or buyer". There are other definitions for collateral, but for our purposes, we're going to use this definition as we can only assume it's the definition used to label this step in the process of referring someone for services. The system is immediately defining the nature of the relationship between the human in need of services and the organ-

ization potentially serving that human. This is transactional. It strips the essence of our humanity away and hands you a file, a large amount of content, written throughout the years, about a human being, with an energy and singular lens of Level 1 listening. Life Works is aware of this and sets this step aside. We do receive these collateral packets. We do not read them, not until we have had a chance to meet and spend significant time with the person being referred to us. We lean into Level 2 listening, setting aside that which has been written, opening ourselves to learning the facts, as they are spoken and written by the person in 'need' of our services and their inner circles of support. This practice provides a bridge for us to walk across and into Level 3 listening.

Level 3 Empathic is where we begin to 'listen with Open Hearts.' We let go of the Voice of Cynicism as a means of seeing through the eyes of another. We begin to connect with another human at the heart-level. This heart-connection provides a space for a deepening, an understanding of a person's authentic Self and a person's authentic reality. This practice of Empathic Listening creates space for the leveling of the field we mentioned earlier in this chapter. Empathic listening humanizes the relationship between ourselves and the other. It connects us in a way where we see through each other's lenses, left with a desire to hold each other sacred. Christine Mayer was an advocate and a person supported for a good portion of her life by an organization called Choices, in Madison, Wisconsin. She wrote a poignant poem...a first-hand description of a life lived, surrounded by supporters and people who could stand to slow down:

If you're going to be with me
You have to listen to me
And you can't just listen with your ears
Because it will go to your head too fast
If you listen slow
With your whole body
Some of what I say, will enter your heart

What a beautiful place to be, if we can only set our intention to embody this listening. True person-centered planning, as a practice, is about slowing down. With the template we co-designed (Beth and Kirk) or any template, we first dispel the notion of time. Listening slow does not afford a drop-down, a checklist set to be completed in a set amount of time. We must set our intention to let go of time as a boundary and sit with people as long as we feel necessary. Once we decide to not let time dictate the process, the process emerges as one to be present with and hold together, with the person we're planning with. That is the intention... to stick around long enough to hear more than the aforementioned surface-level information. The next step, as Scharmer writes, is to pay a high quality of attention to that intention (Scharmer 2018). This leads us into Level 4.

Level 4 Generative is where we begin to listen with Open Wills. We let go of The Voice of Fear and connect to an emerging future whole: a shift in Identity and Self. We fully embody the transformation of consciousness from Ego, to Eco (Scharmer 2018). This is where the magic happens: An awareness of our presence and actions within the greater social field/system and the direct impact we have on the greater whole. As it pertains to person centered planning, as a practice in deep listening Levels 3 and 4, we have the opportunity to embody openness and bravery. We let go of the psychological and physical chains we've been shackled with for centuries. We choose to become the change. We choose to walk into the darkness together, shedding light with each step, trusting in our relationships and honoring people vulnerably saying "this is my life and this is how I want to live it." We draw from these Generative conversations and iterate together as a means of illuminating, as John O'Brien and Beth Mount ask, the path of "What more is possible?" (O'Brien & Mount 2019)

We are grateful for this breakdown of the Levels of Listening as it has provided us with a foundational awareness of how we interface with other people. We are in a position to affect change. It starts with individual awareness and evolves into collective awareness. We as an organization now set intentions with the support of these practices and try our best to have a high quality of attention to them. Circling back to the start of this section, we are mindful of the relationship between patterns and practices. On a micro level, it unfolds with simple things, such as beginning meetings with short meditations to center and ground us. These moments of collective stillness serve to help frame a deeper, more meaningful time together, in that particular moment.

Another micro-practice we engage in are what we call 90-minute sessions with team members. These sessions are always held 'off time', meaning, not during scheduled support time. They can be held at a local coffee shop, restaurant, or even on a hike or walk. The important component to this practice is invitation. Invitation is the key to connection, and unfortunately, is all too forgotten. Humans want to connect. We're hard-wired for connection. However, without intention, we easily get sucked into the overwhelming vortex of reports, checklists and the daily grind of scheduling and oversight of operations. Like we've mentioned, we must start with our intention. Here, the intention is to get to know the people who surround the individuals we support, on a deeper level. We want to engage in Level 3 and 4 Listening with not just the people we're contracted to serve, but with the people who help with the actualization of a good life for that person. We honor and value the notion that *all* people on a team are equally important. These 90-minute sessions are not linked to employment. They are rooted in the idea that all people have a vision for their lives and Life Works intends on understanding the vision for as many people's lives we're a part of and commit to helping realize that vision, one person, one team member at a time.

Over time, these micro-practices cultivate the energy and culture of the organization with a pattern of practices permeating throughout all we do, thus providing a different foundation than we've encountered in our service system amongst other like-agencies or peripheral and collaborative entities. This awareness and the energy emerging from it, will break the cycles we find ourselves in that have led people to segregation and isolation.

When we consistently embody these practices, which we seek in others and in the community, we set forth on a path of authenticity. We honor the Authentic Self in each of us, partnering in relationships as a way of supporting the actualization of real lives. Lives of distinction. Lives of purpose. Lives of value. We hold each other sacred. We hold life sacred.

6 Conclusion

What you're about to read is a message we received from one of our team members, a Direct Support Professional. For the sake of this writing, we've changed the names of the people involved. Lily, the aforementioned Direct Support Professional, is a member of Team Bill. Bill and Lily are relatively new to each other, Lily having been hired in the Summer of 2021. Lily came to Life Works with no direct experience in the field of disability, thus, not influenced by the System, it's definitions of relationship or role and free to connect with Bill. For us, most of the time, it is far easier to provide the space needed for organic relationships to emerge, when we don't have to unpack embedded philosophies, behaviors and tear down walls dividing two humans from connecting with each other. This moment in Lily and Bill's relationship is a manifestation of Level 3 and Level 4 listening. This moment in Lily and Bill's relationship is a manifestation of what is possible when we honor the connective space between two humans sharing space and time with one another...open to mutual and reciprocal learning. Holding each other and this life, sacred.

I told Bill something that we haven't really talked about and I had no idea how he'd react: I told him that my "husband" is actually my wife. "Fred" is actually "Fran". My partner came out to me as a transwoman in December of last year and we've slowly been telling people since. She told her parents just this July. I've let a few things slip: I updated their contact from Fred to Fran (I told Bill that Fran was my cousin at first), but my art project we created together said Lily loves Fran...to which Bill asked 'For your cousin?' I felt compelled to come out to Bill, as he is genuinely interested/concerned about me and asks about my partner and family all the time. So, I took the leap and shared my truth. He was AMAZING! And it really made me happy. At first, he was asking me questions like 'is that weird, is that awkward' then, 'that's very funny'-but I explained how my partner felt and how happy she is now. Bill IMMEDIATELY started using her pronouns and name. He even asked how I support Fran! At the end of the day, before we left each other for the day, Bill said 'I hope Fran has a happy life now'. My heart was so full and my partner was very honored that Bill was so open, understanding and considerate.

For anyone reading the above story, coming from a traditional stance as it pertains to what support between a service provider and a service user should look like, perhaps this leaves you feeling uncomfortable or unsure. We believe getting to a place of feeling unsettled is an important step toward systems change. It is far too easy to replicate services that preclude us from connection. If that were the task, the need for this curriculum wouldn't exist. The system is already quite adept at replication. What we're interested in, and emotionally connected to, is the challenging of these paradigms of thought. We see slowing down to hear someone at an empathic and generative level as human. The system, as presently constituted, may see this as a radical act. It does take radical acts, compiled and spread over time, to shift and move large systems. Breaking through the traditional barriers to human connection is paramount. What emerges is the manifestation of a reciprocal and mutually beneficial relationship between two human beings. Reciprocal and mutually beneficial relationships, and many of them for one person, is what gets people to a place where they feel belonging, which is the northernmost of all the stars guiding us through the system, to a place of full inclusion.

When thinking about people experiencing disability, we must first settle into an awareness and understanding of the individual story. While our past doesn't define us, it certainly can inform the future. Where we must find ourselves is in the present moment. What are the unique gifts found within each of us? What are the gifts of the entire circle of support? How do we connect these gifts and cultivate teams while embodying purpose-driven practices? We believe in relationships: a beautiful symbiosis manifested out of humans giving each other their presence and heart. Once we slow down long enough to hear someone's story, listening empathically and generatively, we reach an awareness of our shared humanity. From here we walk side by side, striving to co-create a world that makes sense for us all.

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