

What More Is Possible for Joaquin?

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Partnership with Joaquin* and his family offers an opportunity to learn how to better support people with developmental disabilities to live in ways that they and the people who love them have good reasons to value, lives that express the human right to live in a place of their choice, enjoy community life and contribute to the common good. He offers this opportunity because of the complexity of the supports necessary for him to thrive.

Policy focus on managing costs through planning and coordinating services can obscure the importance of partnership between those who provide support and the person and their allies. It can seem as if support is a standard commodity to be purchased and delivered as a business transaction. This paper corrects that view from Beth's perspective as a supported living provider who has learned in partnership with Joaquin and his family for nine years.

System managers and providers who decline partnership with people who require complex supports typically do so because they fear the person and the uncertainty of trying another way. Family members who assertively and persistently call for better can stiffen managers' attachment to more of the same. As a result a person is buried, often for life, in settings that congregate and control them as one-of-a-group. The person disappears into an impoverished, physically and chemically coercive routine.** Those who purchase and provide services lock in oppressive structures by avoiding opportunities to co-create tests of limiting assumptions about how to safeguard health, realize developmental potential, balance the costs and benefits of public investment, and seek meaningful community participation.

Joaquin belongs to a family who have kept faith in his responsiveness to family, friends and freedom. They fortified their vision of a good life with him despite a

* To learn more about Joaquin, see his family YouTube Channel <https://goo.gl/CYg6ps> and abilityawareness.com a website he shares with his sister, Diana.

** Sadly this environment can be reproduced outside of institutions. It's impersonality and coercive routines can even be produced in a situation when a person has one or two to one staff as sole occupant of an apartment.

Complex supports are necessary when differences in body, mind and behavior demand...

... the highest level of capacity to personalize and continually improve accommodations and supports in order to minimize a person's risk of exclusion from good opportunities for development, participation, self-determination and contribution, and ... firm commitment, over the person's lifetime, to vigorously champion the person to experience the respect that accompanies valued social roles, the advantages of sharing ordinary community places, the rewards of contribution, the dignity of choice, and the benefits of belonging.*

* For more on this perspective, see John O'Brien. *Innovation & Individualization for People With Complex Needs* goo.gl/0fZL7L

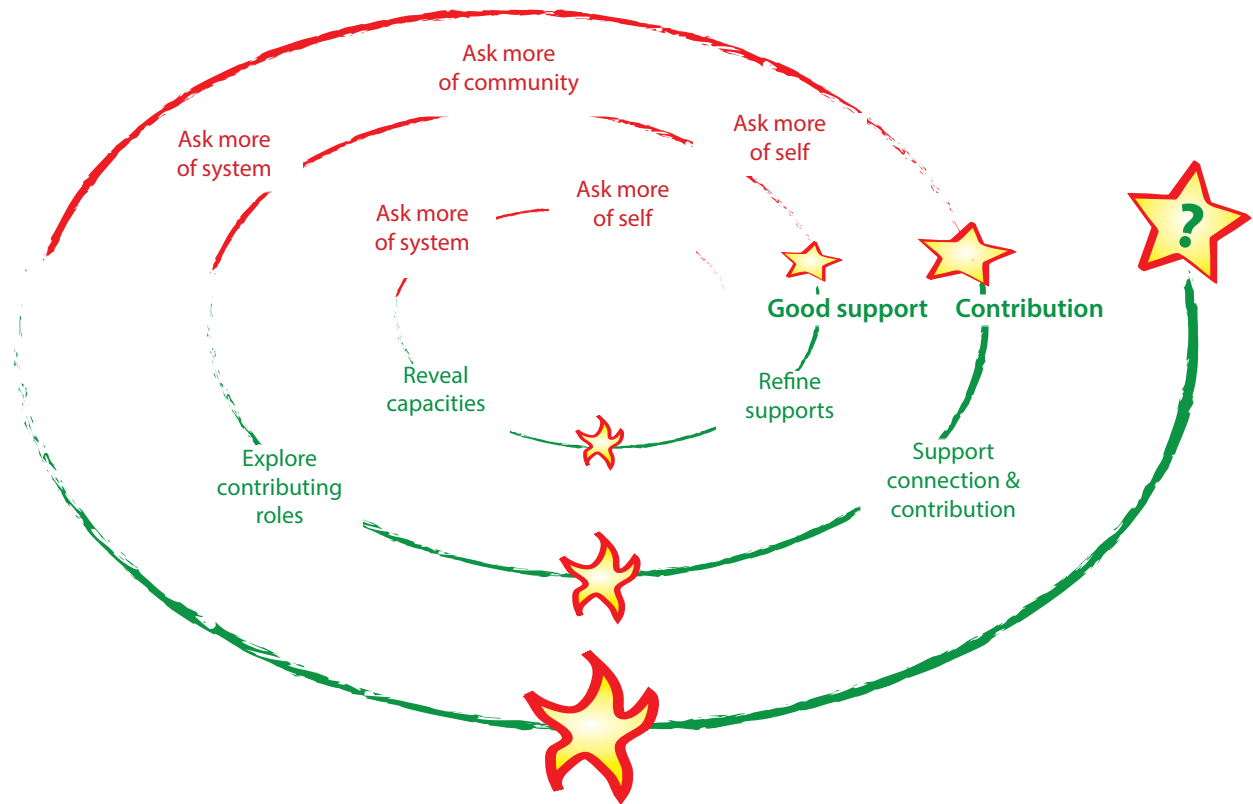
long period of institutionalization*** which Joaquin continued to endure through more than three years of negotiation for personalized supports with a system committed to congregate care. His sister, Diana, researched better ways to understand and respond to his impairments, recruited professional, community and legal allies, learned relevant bureaucratic procedures and persisted. Weekend after weekend, family members drove two hours each way to the Developmental Center to keep their relationship vital.

Family and supported living provider capacity to see and connect with Joaquin's heart and spirit generated tension with those in authority who remained focused on his impairments: autism; a complex and uncontrolled seizure disorder that can require emergency hospitalization and immediate specialist treatment; severe self-injury, injury to others and property damage managed in the Develop-

*** Joaquin spent 22 years in congregate facilities. Eight years in a Developmental Center, seven years in a group home and another seven years back in the same Developmental Center.

mental Center with mechanical restraint; lack of a reliable means of communication, and recurrent GI symptoms. A fixed view that disregards what becomes possible in strong partnerships with committed and competent supported living providers and sets arbitrary mental limits on who can live well outside a group setting and what the system should expend on supported living made negotiations more difficult.

Joaquin, his family and his allies developed ways to cope with the delay. His nephew made a widely viewed video documenting his family's desire for his return to their community which includes his future neighbors' accounts of the relationships they have formed during Joaquin's visits and their desire to welcome him as a permanent resident, as well as expert testimony to the benefits and feasibility of personalized supports.* They developed their understanding of the effects of Joaquin's very substantial movement differences. On regular visits to family homes in the small community they selected with Joaquin in mind, they tested accommodations to these differences. They experimented with alternative means of communication. They advocated successfully for the Developmental Center medical staff to safely eliminate the many psychoactive drugs that family members are sure contributed greatly to his impairments. What his family knew became clear to his allies: Joaquin's days go far better when he is free to move, taking long walks on his initiative, riding as a passenger in an ATV or golf cart, and tending to the environment. (Unfortunately the Developmental Center was unable to build on this discovery, even scheduled walks were deemed impossible because of insufficient numbers of staff.)



Joaquin created a sustaining motto for the movement toward freedom that his family and allies generated by attending to him as a whole person who belonged with them in their community.

*When asked by our mother what meal he wanted upon his return to the community, Joaquin responded, "Steak." And for the rest of his wait for freedom, he continued to claim, "Steak is coming!" Now he says, "I like steak." Joaquin cannot digest steak easily and so he rarely eats steak. But he still says this often when he is happy. "Steak" is Joaquin's metaphor for life quality.***

* A Place to Call Home <https://goo.gl/v4G9AM>

** www.abilityawareness.com

What more is possible?

The diagram* on the left maps a journey of person-centered work. It begins in taking shared responsibility for the question, *What more is possible for Joaquin?* This is a question whose answer can't be computed from his institutional past, it can only be co-created in a real world search for good support, guided by an appreciation of his interests and gifts that grows as support improves. Good support reveals capacities in Joaquin, his allies and his community and refines the fit between Joaquin and the assistance he requires in order to live well. Good support positions Joaquin and his allies to ask again, *What more is possible?* and, in answer, to support him to discover community roles that embody his gifts and sustain his contributions to the common good.

Joaquin's family's unshakable belief in him led them to ask more of themselves. They invested in a substantial and sustained negotiation with a system whose representatives were certain that discharge to a specialized group home and day program represented the most that could ever be expected for him. Month after month they widened their circle of allies, increased their knowledge and refined their strategies for shifting public money from treating Joaquin as one-of-a-group to personalized support for him as a whole person in his community of choice.

Beth –the Director of Life Works, a supported living agency focused on personalized support** – became Joaquin's ally when his sister recruited her in 2008 and continues to coordinate his supports. The rest of this paper describes her perspective on the continuing quest to discover what more is possible for Joaquin.

Co-creating good support

Ask more of self. Joaquin's personality, unrealized potential and current situation, his sister's passion for liberating him to share his family's life, and Beth's

* For a more developed account of this idea, including a discussion of the third turn of the spiral toward generating community activism, see John O'Brien and Beth Mount, *What More is Possible?* <https://goo.gl/cmtf2A> and Beth Mount and John O'Brien, *What More Is Possible?: A Summary* <https://goo.gl/b09gKZ>

** To learn more about Life Works, visit lifeworks-sls.com and read Beth Gallagher and Kirk Hinkleman, *Intentional Teaming: Shifting Organizational Culture* inclusion.com/bkintentionalteaming.html

own experience of the power of personalized support in other people's lives were compelling reasons to become a partner. Responsibility for other people Life Works supports and for leading the whole organization, the effort necessary over time to shift the position of those responsible for coordinating and paying for services, and the extreme complexity of reliably and competently offering Joaquin the assistance he needs called for careful consideration of these questions:

- This is a personal commitment. If things go as we hope, it will be for the long haul. Is this a partnership I can take on?
- This will take much more negotiation with the system than is usual. How can I make time for this? What effect could un-reimbursed costs have on the whole organization?
- Setting up and maintaining Joaquin's supports will need a great deal of my time and attention. How can I carve time out of my schedule for this endeavor?
- I have responsibilities to other people we are already partnered with. How can I realign my workload?
- There are real risks in supporting Joaquin. How can we keep him and his support workers safe? How can we deal with seizure related emergencies when he lives far from a hospital? How can we identify and manage liabilities when the system is not fully behind us?
- This partnership affects our whole organization. How can we build the understanding and commitment we need?
- No matter how carefully we plan, there is uncertainty about what will work best for Joaquin when he moves into his home. How can we build a team that includes him and his family and is creative and resilient enough to deal with whatever comes up?

These questions generated much personal reflection and group conversation. These deliberations resulted in commitment to a partnership that endured and strengthened through three years of negotiation and preparation and has provided support for six years and counting.

Ask more of system. Partnership with Joaquin brings high risk and demand for strong and capable moment-by-moment support. It tests and stretches the

boundaries of supported living. This discomforts managers who still see support to live in a home of your choice as a relatively low cost element in a continuum of residential services. An option suited to people with the skills to manage much of life for themselves, rather than a human right for everyone. To offer the best possible chances for success, Joaquin's allies negotiated a number of accommodations with the support of a dynamic and committed legal team.

- Sufficient funding, which required opening negotiation on frozen supported living rates.
- Funds for two staff, 24 hours a day, and adjustments to the standard budget template to allow a higher rate of pay to attract and retain people with the necessary capacities to respond to Joaquin's difficult-to-predict times of extreme need and to actively and creatively support his everyday life as a family and community member.
- Regular availability of specialist nursing, positive behavior support, and communication consultants, chosen for their skill and their ability to connect with Joaquin and his journey into community life in his own home.
- Adjustments to usual assessment procedures for supported living: allowing three times more time for assessment than is typical; assessment begins with Life Works staff spending time with Joaquin at the Developmental Center, on his living unit; mileage paid for assessment related travel; assessment continues after the move to allow adjustments to support as Joaquin experiences his new home and community.
- Accommodations in the time of transition: full staffing while the assessment continues in his new home; a plan for familiar Developmental Center staff accompany Joaquin and stay with him for the first three days in his new home (in the event DC staff left sooner than planned).

Reveal Capacities. As a member of a family who set down roots in a chosen community Joaquin has access to a richer and more diverse network of relationships and opportunities than he had as a Developmental Center resident, where his social world was mostly confined to the staff and residents of a single locked unit.

Team Joaquin, which holds him at the center, grew to include 16 others: family, support workers, consultants. His sister, who for a time shared case management with Beth and worked as a team member, modeled a relationship of no fear, shaped a culture of peace, and mobilized her knowledge of Joaquin and the community they now share. Diana's favorite quotation from Peyton Goddard, a wise woman with autism who communicates through supported typing, expresses the spirit she calls forth:

Esteeming each person as vastly valuable seeds their peaceful self.

As the team practiced in this spirit, capacities have emerged.

- Joaquin worked hard in response to the opportunities offered by closeness to family, a welcoming community and a team committed to learning with him how to offer good support. The whole team's experience of responding to severe seizures and periods of dysregulation built confidence in their collective ability to deal with difficult times. Incidents of self-injury and dysregulation decreased, though they have not yet disappeared.
- Nursing and positive behavior support consultants have found fertile ground for their practice.
- Emergency response to life threatening seizures in a small community with poor cell phone service a least a half an hour from the nearest hospital is a major and continuing concern. The Fire Department has become an active partner in emergency response. The hospital has become familiar with Joaquin's situation, including his adverse reactions to some drugs. Neighbors along his usual walking route walks hold walkie-talkies that put them in immediate contact with help should Joaquin need it.*
- The people who gather at the Trading Post, a general store that serves as the local social center, have welcomed Joaquin and offered neighborly support.
- The local handy-man adapted and repairs Joaquin's home.

Adjust supports. As Joaquin and his team continued to improve their responses to occasional emergencies and everyday opportunities, Diana left her case management role and continues to participate actively as family member and guardian.

* As local cell service and access to WiFi has improved this accommodation is no longer necessary.

- Beth chose to share case management with another Life Works staff member who has a gift for managing the mass of system related detail generated by the complexity of Joaquin's support.
- Strengthened relationships with hospital staff and negotiated at-home use of Diastat and oxygen has improved emergency response to seizures.

Support contributing roles

Life Works honors a practice of refreshing its support by regularly asking, *What is the next best question?* This activates support for Joaquin's exploration of ways that he can contribute to the well being of his family and community, the second spiral in the search for *What more is possible?*

- Ask more of self and team.** Even response to crisis can become routine and, without renewal, initial gains can be accepted as a good enough stopping place for Joaquin's quest for a good life in his community.
- Re-commit to Joaquin and his potential for an even better life. Keep building on small victories; don't get stuck in a rut or settle for low expectations.
 - Sustain monthly family meetings.
 - Look for better alternative communication strategies.
 - Look more deeply into improving health and wellness: healthy diet; better understanding of allergies; optimal weight; skin and dental care.
 - Redesign the team's communication system.
 - Work hard on helping Joaquin realize that his words have value and power. Years of neglect and being ignored taught him that his words meant nothing. Now he uses a Yes / No board extremely reliably and communicates full sentences fairly reliably using supported typing.

Ask, and support, more from community. Joaquin attracts some offers from his neighbours. Other resources and accommodations can be negotiated.

- A neighbor offered offers Joaquin motorcycle rides. Another offers rides in his off-road vehicle.
- Joaquin has an account at the Trading post that makes him able to purchase snacks and small items for himself.

- Other regulars at the Trading Post have joined community conversations about work opportunities for Joaquin.
- Doctor visits are stressful. Joaquin's physician accommodates by making "car calls" (meeting Joaquin in the car when he reached the hospital).
- A dietitian developed an interest in Joaquin and offers her assistance at a reduced rate. A better diet makes a noticeable difference.
- Joaquin experiences better seizure control from an implanted VNS (Vagus Nerve Stimulator), which provides individually programmed regular stimulation. An extra burst of stimulation, triggered by an external magnet, can help to stop a seizure when Joaquin lets people know that a seizure is imminent. As a back-up for a time, a neighbor held and learned to use the magnet as a back-up to Joaquin's staff.

- Ask more of system.** Receiving the intensive, qualified, stable 24 hour personalized assistance that he needs through one supported living agency makes Joaquin an exception in the system that pays for his services. While residence in the Developmental Center is more costly than Joaquin's personalized supports, his budget is high in comparison to more typical expenditures on supported living.
- There is a common assumption that supported living costs should decrease, based on monthly reviews. This adds unnecessary uncertainty and transaction cost because his needs for support are very unlikely to vary from month to month. Negotiating a longer budget review period with more realistic expectations about reduction in expenditure relieves stress and saves time.
 - Employing the nurse, behavior specialist and dietitian as consultants to Life Works rather than system contractors adds flexibility to their relationships and contributions.

Explore contributing roles. Despite years of good work and learning, some difficulties persist. And, as with any set of long term relationships, there have been times of conflict and hard conversations. But commitments are stronger than conflicts, so Joaquin has many reasons to say, *I like steak*, in celebration with his allies of improved life quality. He has found a variety of contributing roles that make a difference to his family and his community and allow him to express more of himself.

