

## Supporting a Journey From Chaos to Contribution

This documents the organization of assistance for a person with a developmental disability, known here as E. It was constructed in September 2016 by John O'Brien based on a group interview with some of the people most involved in supporting E's journey from chaos to contribution. It takes the perspective of those responsible for providing E's assistance and reflects their intentions and design without conscious evaluation. It is not a portrait of E or a statement of a plan for him. It describes the supports that he counts on.

The framework for this description is borrowed from Systems Thinking.\* The iceberg metaphor invites a look below the surface to the deeper aspects of assistance that account for what we see; in E's case a period of developmental growth that gives him the opportunity to participate in an expanding variety of community roles. It calls our attention to four aspects of assistance at work below the surface.

**What we see** is shaped and sustained by recurrent **Practices and Patterns of Activity**: daily, weekly, monthly routines and schedules; physical and social responses to a person's impairments; social rituals; responses to requirements and rules; ways of reflecting on, renewing and updating what's meaningful; decision making and exercise of authority. The shape of these practices embody the form that power takes in the daily life of people and their assistants.

**Structures** contain **Practices and Patterns of Activity** by organizing available resources: boundaries with communities; means of resourcing assistance and the accompanying requirements; ways people are grouped; arrangements for collaboration and co-production; the physical setting, its design and ownership; structures for allocating assistants and managing their responsibilities; constitution of authority and supervision; formal and informal role definitions; allocation of responsibility for tasks and requirements; forms of learning; policies that influence relationships and everyday life (e.g. risk management); provision for transportation; connections among agencies;

**Stories** guide action by providing an account of the identity of the person assisted and the purpose of assistance (answering who we are and why we do this): a narrative that communicates the right way of proceeding, an understanding what is valuable, and beliefs and assumptions about what is possible and what is effective. Stories transmit mindsets about disability, community and society and provide resources for framing issues, making meaning and justifying decisions. Stories offer coherence: we do things this way because we see that the people we assist and our community and system are that way.

**Source – What gives life**: the pattern of relationships that shape awareness and attention and so the living form assistance takes. It is the social field that gives life, maintains and renews the stories, structures and practices that create what we see. Relationships that are stuck in disrespect of people's citizenship, disregard of their capacities and distance from their human experience generate segregation and control. Relationships open to mutuality, shared search for capacities, and collective struggle for access to valued social roles generate new and better designs for assistance as people discern and move into roles that develop and express their citizenship.

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\* In *Leading from the Emerging Future: From Ego-System to Eco-System Economies* (2013), Otto Scharmer and Katrin Kaufer apply this framework to the development of economic systems. Their understanding influences this one.

**Options in Community Living** ([www.optionsmadison.com](http://www.optionsmadison.com)) is a locally based organization committed to offering individualized support that assists people with developmental disabilities to live in homes that they themselves lease or own and self-direct their lives and the assistance they require. They act from the belief that community living is for everyone, regardless of the amount and kind of assistance they need. They have recently focused their concern for people with complex and challenging needs in a dedicated Team that supports a number of people, including E.

**Community TIES** ([cow.waisman.wisc.edu/ties.html](http://cow.waisman.wisc.edu/ties.html)) is funded by Dane County to provide a variety of supports to people with challenging behaviors, their families and allies. These supports are available, as needed, without additional cost to the person's individual budget. E has made use of each of these services: Crisis Response offers additional direct support in people's own homes or in a Safe House. TIES Clinic provides psychiatric services and consultation. The Adaptation and Modification Program adapts environments to increase safety. Rhythms provides consultation and learning opportunities for staff who support people with complex sensory and motor differences that affect a person's ability to regulate emotion and movement and communicate.

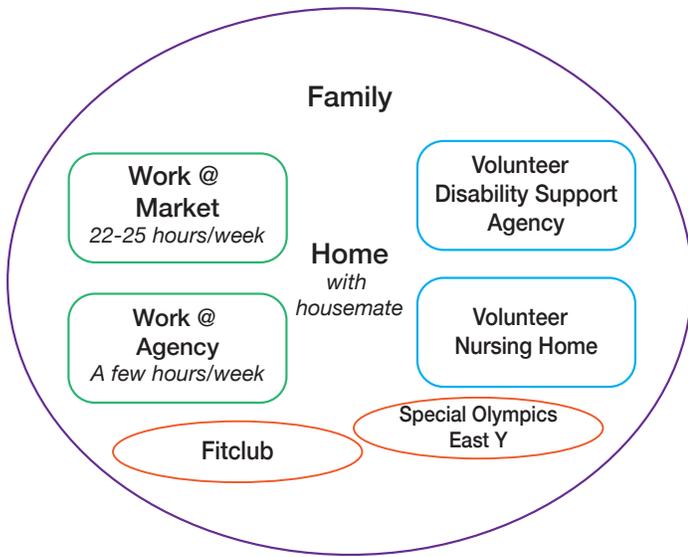
**Consultation.** Dane County invests in ongoing consultation from local experts (such as E's psychotherapist and his vocational consultant) as well as carefully structured engagements with experts who work at an international level. E has benefited from both forms of consultation. **Rhythms** offers ongoing learning and follow-up to consultations on *neurophysiological difference*. This perspective and the practices that flow from it are less common in the Developmental Disabilities field, which has been heavily influenced by a behavioral perspective. For a brief introduction see <http://aspergersquare8.blogspot.com/2009/06/conversation-with-martha-leary.html>.

## What we see

A shift, over four years of intensive individualized support, from extreme self-harm, frequent police involvement and hospital admission to participation in contributing community work, volunteer and civic roles. Reduction from 2-1 to 1-1 support. No police involvement since 2013, no hospital admissions since 2012.

<b>Practices</b>	Roles, routines and tools that produce a steady increase in E's capacity for self-regulation. Regular time with family. A negotiated routine that combines community work, volunteering and recreation with mindfulness and calming practices. Mutually agreed ways to respond to dysregulation. Staff focus and capacity to adapt to moment-to-moment changes in E's vulnerability or his readiness to increase responsibility and competence.
<b>Structure</b>	Self-Directed Support budget provides a well supported, E-focused team that offers 1-1 assistance 24 hours a day. Community roles –including a half-time job– offer structure and opportunities for meaningful contribution. E leases a house adapted to increase safety and now shared with a housemate. Regular consultation and continual opportunities for reflection and learning about effective ways to strengthen E's self-regulation and expand his opportunities for contribution encourage continual updating of practices.
<b>Story</b>	Escalating failure of practices based on understanding E through psychiatric-behavioral lenses led to a complete breakdown of his supports and short-term institutional placement. Investment in consultation and learning opportunities allowed a complete revision of his assistance based on an appreciation of the effects of trauma and differences in sensory processing and bodily control. This understanding led the team to adopt practices intended to develop self-regulation, confidence in the capacity to stay safe, and ability to contribute through increasing participation in community life. Respectful, collaborative relationships, shared learning and negotiated boundaries work. Attempts to exercise power over E fail dramatically.
<b>Source</b>	E has a gift for recruiting people into his life. As he and his assistants develop capacity to deal effectively with dysregulation he shows up more and more as a proud and capable worker, volunteer and companion. He shows a deep desire to increase self-regulation and make a positive difference to others that pulls those who assist him into new learning. E's mother has a profound sense of his capacities for development and contribution, the will to be an active force in his life and the desire to collaborate with his assistants. Options and Dane County share a longstanding commitment to doing whatever it takes to make institutional placement of any kind unnecessary. Rather than abandon E when things were at their worst, they chose to re-design his supports by challenging assumptions at their roots.

**What we see** E leases a house adapted for his development, which he shares with a housemate.



He works in a market 20-25 hours a week and for a human service agency a few hours a week depending on their need for his services.

He volunteers at a nursing home and for another human service agency that assists people with disabilities to increase their independent living skills.

He is an active participant in several fitness and recreation groups.

Except for some time with his family, E is constantly accompanied by an assistant who supports him to use the tools he has learned to manage emotional dysregulation.

E teaches others his self-regulation strategies.

E has created significant changes in collaboration with his supporters since together they implemented a complete redesign of his supports in June 2012.

<u>From</u>	<u>To</u>
2-1 staff	1-1 staff*
Sole occupancy of his house	Having a housemate
Days spent mostly at home or on outings with 2-1 staff	2 paid + 2 volunteer jobs
Staff always in line-of-sight	Staff present in work & volunteer settings but not in line-of-site unless needed
Multiple & frequently changed psychiatric medications	No psychiatric medications

\*Moving from 2-1 to 1-1 staff was a careful process that took more than 2 years.

	What we saw 2011	What we see since June 2012
ER Visits	12	0
Police Interventions	11	1
UW Hospitalizations	3	0
IMD/ICFMR Admissions	6	0

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## Practices

The moment-by-moment purpose of E's support is to steadily increase his confidence that he can trust himself and his supporters to know what to do when emotional dysregulation threatens his (and others) safety, autonomy and capacity to live as he would prefer.

E's assistance is only as effective as his relationship with his assistants and their capacity to respect his autonomy and collaborate rather than attempt to impose control. They know that if their relationship becomes about power they are failing. They learn with E by sharing intensive training and regular reflection. Together with E and his family they are building a common understanding of neurophysiological difference and trauma and what works to manage its ill effects.

In collaboration with his staff team and consultants, E has learned tools for calming and regulating himself. Calming techniques are a part of his daily routine. These tools also encourage noticing the earliest, smallest signs of dysregulation, pausing and slowing down to implement self-regulation strategies. The most fundamental tool is mindful attention to breathing and shared breath control, which has taken a variety of forms.

E finds stories a helpful support to his planning and problem solving. His assistants share stories of successful problem solving or resilience in a difficult situation as a model of sense-making. They think out loud when identifying a real time problem and invite E to join in thinking it through.

E has been working with his therapist to develop a core vocabulary that allows him to discriminate what he is feeling and whether its source is physical discomfort or emotion.

A daily routine draws and redraws clear boundaries. A schedule of at home activities, negotiated with E at regular meetings, includes a daily pattern of movement activities. E is active in suggesting changes in their routine—early efforts to incorporate yoga into the daily routine were replaced with other forms of movement and he has invented and enjoys leading and teaching his own breathing and mindfulness activities.

As an example, E and his staff collaborate on implementing a “Leaving the House Checklist”, which they revise as circumstances change. It assures review of important matters such as how well rested he is, a check of whether he is carrying anything he might ingest, and what his current pattern of choice making says about his safety outside the house.

E's team take care to respect his dignity. For instance, his assistants needed a safe way to take a hold of him if he became dysregulated while they were out together. They settled on a backpack and any staff person accompanying E also wore a backpack to avoid singling him out.

Frequent phone check-ins with important people in his life, such as his mother, the Team Coordinator, Community Support Workers, Lead Staff and, re-establish their continued presence in his life.

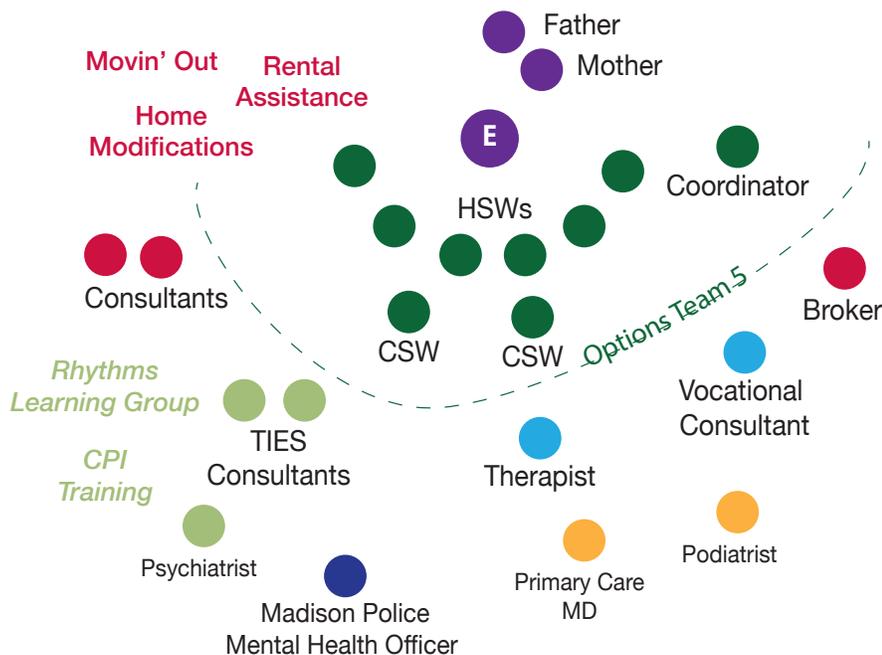
E has in the past found a weighted blanket and gloves helpful to support sensory integration, and knows he can request them or decide to use them when staff suggest.

E's home has been modified to minimize the possibility that he will find something harmful to ingest. His assistants control perimeter locks and can lock zones within his house. Use of these safety measures has steadily decreased.

Should there be times of extreme dysregulation, E has a safe room which can be secured (13 times in 2012-2013 and not at all since then). Two extreme incidents early in the new support design established that his assistants could and would take responsibility to use the safe room if he were unable to self-regulate.

## Structure

E's adoptive mother and father are a vital part of his life and support. He spends time with them weekly. His mother is a key member of the team responsible for designing and updating his supports.



E has the final say in choosing his assistants.

E rents his home from Movin' Out, a housing agency whose mission is to provide integrated housing options for people with disabilities. The home has been extensively modified to increase E's safety and the safety of his assistants.

Nine staff employed by Options in Community Living share responsibility for day-to-day assistance: six Home Support Workers, two Community Support Workers and the Team 5 Coordinator. Regular household meetings include E and his whole direct support staff.

E has a Broker who is responsible for E's support plan and assisting in the management of his Self-Directed Support Budget. She is actively involved with his support team and has a special interest in improving assistance to people who experience neurophysiological differences.

E has regular appointments with –and calls as needed– a psychotherapist who specializes in trauma and work with people with DD. She was involved in planning and implementing E's supports and continues as active member of his team, providing consultation and counsel to staff.

A specialist in supporting people with neurophysiological differences consults with E and his team. A number of those who assist E are members of *Rhythms*, a cross-agency learning group sponsored by Dane County that focuses on improving understanding of and support to people with neurophysiological differences. *Rhythms* is guided by the work of a consultant who works internationally on support to people with communication, sensory and motor differences. She has been directly involved in the design of E's supports.

E has a Vocational Consultant who provides assistance as needed.

E's Team has support from TIES in offering active positive support and dealing safely with crises. His psychiatrist was also affiliated with TIES Clinic.

The Madison Police District's Mental Health Officer had a position among E's supporters. The police have not been active in his life since 2012.

Intensive investment in learning –careful selection, preparation and introduction of staff; regular team meetings that include reflection; participation in learning opportunities and consultation– all play an essential part.

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## Story

In consequence of neurophysiological differences in movement and sensory processing coupled with trauma that began before his adoption, E lives with vulnerability to extreme emotional dysregulation. Dysregulation can show up in panics and rages, self-harm, ingestion of objects and medications and extreme property destruction.

Relationships with assistants he trusts are the foundation for good support. In the past, the inability of the people he counts on to keep him safe led E to lose confidence in himself and those close to him. He sought safety in dangerously escalating efforts to involve the police and the hospital in his life.

E can be frightening when dysregulated and his ability to find medications or dangerous objects to swallow is acute. The damage he does when dysregulated concerns and distresses him. Because other's efforts to take power and impose control makes self-regulation even more difficult for E, he and his supporters got trapped in a vicious cycle which was broken when his supporters found a new way to understand his differences and how they can collaborate with his efforts to self-regulate.

As disciplined attention to collaborate in E's discovery and use of effective tools for self-regulation has increased his confidence and trust in his supporters capacity to be of real help, his opportunities to contribute to others and enjoy himself through participation in his community has steadily increased. When roles are well structured and expectations are clear, such as at work, the role itself is a source of support for self-regulation.

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## Source: What gives life

E has a gift for recruiting people. His mother says, "He learned two survival skills in the orphanage: to make people love him and to use violence to get what he needs." His developmental quest is to let go of the need for violence and let love support him to live as his best self. Recognizing and actively supporting the hard everyday work and demanding learning that this takes from him and the people who assist him increases resilience.

E's mother holds a deep belief in his desire and capacity to develop and contribute to other's well being. In the past, she experienced frustration with her inability to influence the escalating failure of a succession of efforts to control E with psychiatric drugs and coercive interventions. She is now a valued co-creator of support through relationships that allow E to show more of who he is at his best.

Options and Dane County share a longstanding commitment to making institutions unnecessary by offering everyone, regardless of their level of need for support, the assistance they need to live in their own home and have real opportunities for integrated employment and participation in community life. E severely tested this commitment over three years of increasingly dangerous behavior. Rather than reject E, Options collaborated with E's mother, his Broker and County Managers to revised their story of E's need for assistance in light of shared learning about neurophysiological difference. They completely redesigned E's supports, investing considerable time in recruiting and training staff. This not only cost money, worse, it required E to remain at Southern Center for seven months while his team got organized.

E pulls his supporters past their boundaries. Committed relationships are non-negotiable in developing E's trust and confidence in himself and those who support him. Some staff members willingness to go well above and beyond typical staff expectations forms the foundation for E's progress in overcoming emotional dysregulation. Options culture supports these intense relationships.