

Working In Complexity

Lessons For System Change From Support Coordination

John O'Brien and Patti Scott

Summary

We advocate a strong view of inclusion and self direction that disrupts most current ways that publicly funded assistance to people with ID/DD are organized and delivered. Progress in realizing these values calls for deep change.

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We find the **Cynefin** framework a helpful way to guide the design and practice of Support Coordination.* **Cynefin** distinguishes **ordered** situations –in which best practice and good practice define good solutions– from **complex** situations, where adaptive solutions are discovered through purposeful action in particular situations.

Progress toward inclusion and self direction requires the capacity to work in **complexity**.

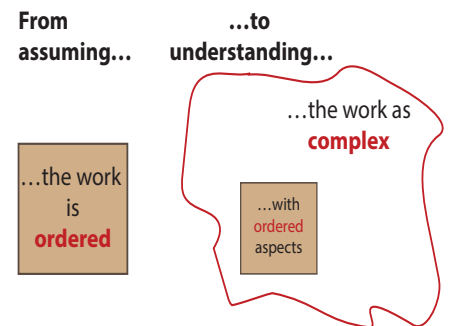
- Different understandings of inclusion and self-direction lead to significant disagreements about how to implement policies including the recent *CMS Setting Requirements* and *Employment First* policy.
- These disagreements can only be effectively resolved by generating social inventions that test a variety of ways to offer people with ID/DD individualized support to experience self-direction and valued roles in community life and broaden and build from what works.
- These social inventions must be co-created with people with ID/DD and the diverse people with whom they participate in community life. They can't be imposed.

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Under conditions that encourage them to work in **complexity**, Support Coordinators can join and encourage some people with ID/DD and their families to co-design, co-develop and direct forms of assistance that support them in valued community roles.

Unfortunately administrators of public funds for assistance to people with ID/DD often act as if as if the context for Support Coordination were **ordered** and effective performance were a matter of implementing **best practice** as administrators define it. This expectation diminishes the contribution Support Coordinators can make to real change and consumes attention in compliance driven activity.

Past practice shows conditions that have allowed Support Coordination to work in **complexity**, with good results. Whether those conditions can be retrieved and strengthened remains to be seen. If the grip of belief in an **ordered** situation is too strong, people with ID/DD and their allies who choose the leading edge of inclusion and self-direction will need to create new forms of assistance to make the best of their **complex** environment.



*This function has many, changing names. Here Support Coordination stands for service coordination, service brokerage, care or case management and other similar roles.

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Policy calls for co-creation of new paths

CMS Rule

*Home and community-based settings must...**

[Be]integrated in and support full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS....

Facilitate individual choice regarding services and supports, and who provides them.

NJ DDD Key Themes**

Individual Choice. The Division is committed to providing increased opportunities for individuals with developmental disabilities to make individualized, informed choices and self-direct their services.

Shift from Segregated Settings/Supports to Integrated Supports. Individuals with developmental disabilities in New Jersey should be afforded the opportunity – like everyone else – to fully participate in their local communities.

Employment First. Competitive employment in the general workforce is the first and preferred post education outcome for people with any type of disability.

* Edited from CMS (January 2014) [Home and Community-Based Setting Requirements; Final Rule](#) p. 3030.

** NJ DDD (April 2017) [Supports Program Policy & Procedure Manual 4.0](#), p. 13.

US federal and state authorities responsible for funding and regulating services to people with intellectual and developmental disabilities (ID/DD) call for changes in service planning and provision in order to support real-life benefits: living, working learning and playing included in community as contributing citizens, and choosing services to support their individual experience of these benefits. As this reflection on shifting functions for a Support Coordination agency in one state shows,* at the same time that they call for significant change, the same authorities are depleting an important resource for developing the capacities necessary for change. Efforts to manage cost, impose multiple mandates, and command the process of change undermine the contribution that Support Coordination has demonstrated it can make by mobilizing people with ID/DD and their families.

These changes require a shift from managing people with ID/DD as one of a marginalized group to designing and delivering individualized support that gives people with ID/DD the same level of control of their lives that any citizen expects and expands the personally meaningful opportunities available to them through inclusion in their communities. While increasing public investment in DD services improves conditions of life at the margins of community, most people with ID/DD remain in special social spaces set apart for THEM. The boundaries of these spaces are set by the reach of a family's social orbit and the capacity of available services to personalize assistance and support people to support participation in community life. Current reality leaves too many people with ID/DD excluded, isolated and controlled by service routines and policies.

Current practice leaves too many people and families with the idea that their lives must happen within the limits imposed by the structure of current services. Self-direction expands with recognition of possibilities for co-creation that comes when people and families recruit a circle of support, participate in networks and focus attention on living a life that expresses their purposes and identity.

Real change is impossible without the active participation of people with ID/DD and their families who are willing and able to take responsibility for co-creating the supports that bring them into community life in new and valued ways. Personalized supports that assist a person with ID/DD to live a full life can't be imposed. Effective supports to inclusion can only be co-created with people who hold a clear intention to be in control of their journey to cross excluding boundaries and develop valued social roles in community life.

* Patti was a support broker for many participants in New Jersey's first self-determination initiative, which began in 1997. Her interest in the difference Support Coordination can make has continued and she is currently CEO of [Neighbours, Inc.](#), an organization that offers Support Coordination to about 2,000 people with ID/DD. Neighbours, Inc also offers individualized support to 30 people who live in their own homes.

Through 2016 Patti carried out a process of reflection on Support Coordination through a variety of conversations on four different occasions. Along with Monique Dujue Wilson and Erwin Wieringa, John visited as a critical friend. This paper builds on what John and Patti learned from this inquiry. We are grateful to the people with DD, family members, collaborating service providers, support coordinators, managers and Neighbours board members who participated in these conversations.

While we ground this discussion in the experience of a New Jersey agency, conversations with people in other places suggest that it is more generally relevant.

Our perspective on Support Coordination

The primary function of Support Coordination is to assist people with ID/DD to identify what defines a good community life for them, decide on the best way to mobilize available resources to live that life, and help with discovering opportunities and adapting to changes.^{*} This is an active, conversational process that often unfolds over months and years as people and families engage uncertainties, explore possibilities and build on what works to make the most of their developing situation. At its best, Support Coordination organizes recurring conversations that engage person and family with other people with disabilities, other families, friends and allies, community members, and providers of assistance. Conversation motivates and guides creative engagement with constraints: people may need to negotiate accommodations to support community participation; there may be concerns about safeguarding people's dignity and safety; recruiting and retaining trustworthy and capable assistants is challenging; each public benefit has its own requirements and exclusions. Good conversation involves thoughtful consideration of the personal implications of public policy and organizational values that encourage self-direction and inclusion. Support Coordination can make a positive difference at different scales. Positive person-by-person changes accumulate, encourage others to act, influence adjustments in the provision of support, and open more space for inclusion in community life.

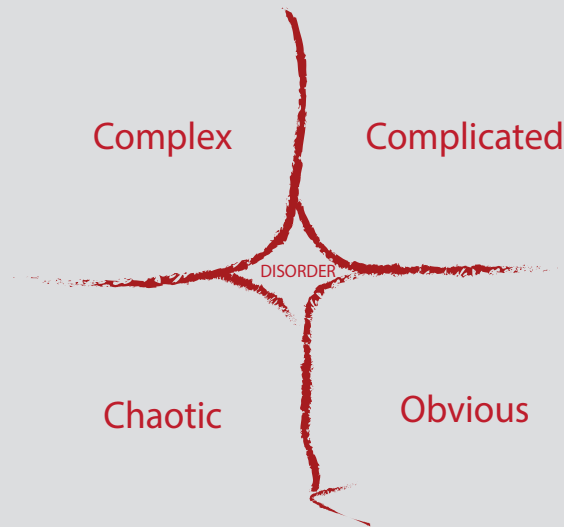
There is a much greater chance of benefit if there is a good fit between the kind of work necessary to effectively support choice and inclusion and the way Support Coordination is organized and practiced. We have found the **Cynefin Framework**, developed by Dave Snowden and summarized on the next page,^{**} a helpful way to think about and do the work of Support Coordination.

Different situations call for different decision processes, so **Cynefin** adds an orientation-to-context step to the decision making process, asking, *What is the nature of the situation we intend to change?* Without this step people employ whatever strategies they are most familiar with and so reduce the chance of wise decisions (the state of failing to determine context is called **disorder**). Situations are called **ordered** when people agree on stable and reliable ways to achieve desired results. Ordered situations are **obvious** when all involved agree on **best practice**. They are **complicated** when analysis or expert advice is necessary and sufficient to create agreement on **good practice**. Situations are called **unordered** when there are competing ideas about what is possible and what to do and the way to desired results can only be discovered in action. **Unordered** situations are **chaotic** when the lack of constraints on action result in great variation. They are **complex** when paths to desired results can only be discovered by acting with purpose. **Emergent practice** discovers a path by repeating safe-to-fail experiments, amplifying what works and dampening what does not.

^{*}This account summarizes responses to an appreciative inquiry into what people, family members and experienced Support Coordinators identified as characterizing Support Coordination at its best.

^{**} Snowden is developing his ideas in the world of knowledge creation to inform policy and software development. The summary in this paper will be easier to understand if you take nine minutes to watch [Introduction to the Cynefin framework](https://www.youtube.com/watch?v=ILhKWC) on YouTube. ([goo.gl/ILhKWC](https://www.youtube.com/watch?v=ILhKWC)). We are grateful to [Chris Corrigan](#) for introducing them to Patti at Art of Hosting trainings.

The Cynefin Framework for Decision Making*



Cynefin (Welsh • Kih-neh-vihn): habitat; locality; the feel of the environment we stand in; place of multiple belongings which shape us in ways we can only partly understand.

Different situations call for different approaches to decision making. No domain is superior to any other, the point is to act in ways appropriate to the domain that forms the context for action.

Domain		System Characteristics	Decision Process
Ordered	Obvious	Cause-effect relationships are known, stable & the path to desired results is predictable. It's apparent to those involved: <i>We've been here before & we know what to do.</i>	Sense-Assign to the correct category-Respond with Best Practice. Monitor compliance. Look for efficiencies. Check lists work. Mis-application results in rigidity that easily collapses into chaos .
	Complicated	Cause-effect relationships are knowable through analysis. Those involved agree, <i>We are guided by someone with a method for finding a right answer.</i>	Sense-Analyze-Respond with Good Practice. Enlist expert help & follow advice There are multiple pathways to desired results; don't enforce just one.
Un-Ordered	Complex	Cause-effect relationships are unknowable & unpredictable. Small differences in initial conditions can make a big difference. Constraints influence actors & are influenced by them. There are dispositions & attractors that influence behavior & create patterns. People have competing ideas about what is possible & what to do. <i>We discover the path by traveling this space with purpose.</i>	Probe-Sense-Respond to shape Emergent Practice. Increase flexibility by setting wider boundaries. Make time & space for reflection. Try a variety of safe-to-fail experiments. Amplify what attracts the co-creation of good stories; dampen what attracts limits on possibility.
	Chaotic	The situation is unstable and temporary. No patterns. Actors are independent & there are no effective constraints. If this is on purpose, <i>We are in a period of radical innovation</i> ; if accidental, <i>We are in crisis</i> .	Act-Sense-Respond through Novel Practice to move the situation to another domain.
	Disordered	No determination of context; decisions made on the basis of habit or favorite method.	

* **Dave Snowden** authored and continues to revise this framework. This page quotes and paraphrases his writing. Connect to his work through the [Cynefin Centre](#) at University of Bangor (Wales) and [Cognitive Edge](#). The best short introduction we have found is through two YouTube videos [Introduction to the Cynefin framework](#) and [How to organize a children's party](#).

Twenty years experience with the results of Support Coordination leads us to this position. **People with ID/DD, their families and their communities will be better off when it is easy for Support Coordinators to move into and out of complexity with them.** This would be uncontroversial if current administrative trends were not pushing to treat the work of support coordinators as if it were entirely **ordered**.*

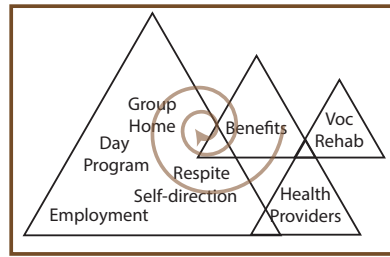
Good decisions depend on making sense of a changing environment in order to act effectively in it. **Cynefin** does not have a favorite domain and neither do we. Because each domain offers an approach that best fits a situation, it is always worthwhile to move out of **disorder** –where we simply re-apply whatever approach is most familiar and comfortable for us and matching action to situation is a matter of chance– and thoughtfully identify the the relationships and practices the situation we want to change. Crisis precipitated by sudden loss of a family caregiver or provider default demands immediate and effective intervention in **chaos** to restore stability. Important aspects of Support Coordination are **ordered**. The correct ways to write an ISP or report an incident are **obvious**, specified in a state issued **manual** of policies and procedures. When matters are **complicated**, a hierarchy of supervision offers guidance necessary to make a good call. Generating a person-centered plan that moves off the computer screen and translates into action for inclusion is very often **complex** because people encounter new, uncertain territory. Applying for rental assistance is typically an **ordered** process; deciding that a person apply as they move from a group home to live with individualized support in their own home is often **complex**. We don't think that every aspect of Support Coordination is **complex** but that Support Coordination makes its best contribution when people and their allies can freely work together in complexity: moving beyond existing boundaries by designing, trying, learning from and modifying safe-to-fail experiments in self-direction and community living.

Cynefin maps situations by identifying **boundaries** that define fields of action, **attractors** that draw and focus attention, and **tendencies** to reproduce particular results.

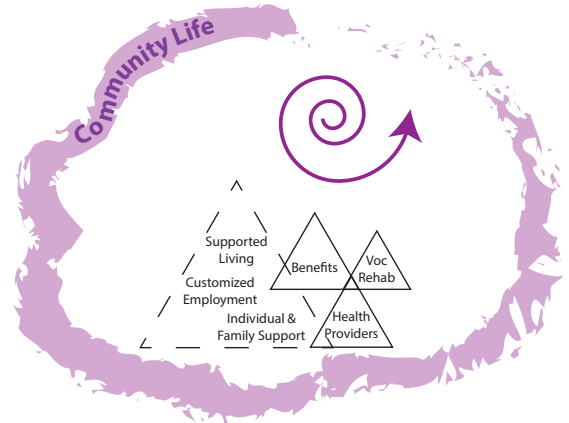
In most places today, public authorities set boundaries that occupy Support Coordination with managing the interface between individuals with ID/DD and health and human services providers. The strongest attractor absorbs attention in servicing Medicaid long term care machinery by complying with state designed and required procedures and demands for documentation. Compliance is complicated because documenting indicators of a Christmas tree of concerns for health and safety, avoiding abuse, fraud detection, quality assurance, cost control and data collection have accumulated as conditions of funding. Responsibility for implementing and monitoring compliance with consent decrees and court orders can add further detail complication. Occupation with this attractor makes Support Coordination an amplifier of the system's tendency to produce a gap between what it reliably produces and its stated aim of building capacity to support inclusion and self-direction.

* Please keep the "as if" in mind as you read. This paper applies what we know of **Cynefin** to Support Coordination as we understand it through experience and inquiry. We don't suggest that administrators or support coordinators currently think this way. Indeed, our goal is to encourage them to do so.

Less effective boundaries
lock energy inside
existing services



More effective boundaries
align services with building
more inclusive community

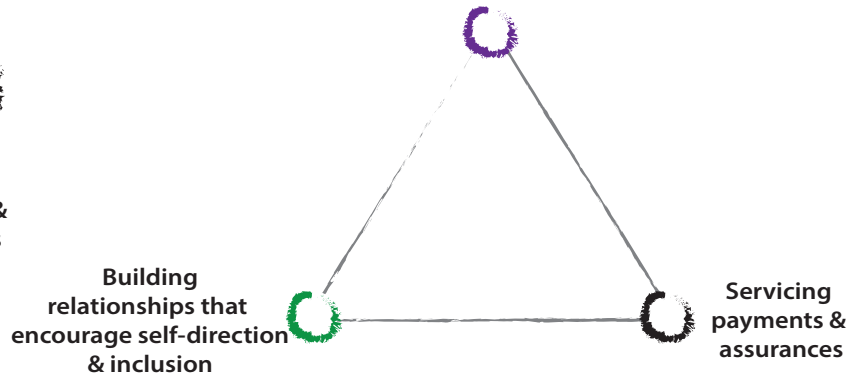


Less effective attractors
absorb most energy
in compliance



Servicing
payments &
assurances

More effective attractors draw
creative attention to
co-creating real change
**Co-creating self-directed
supports for inclusion**



Reflection on previous ways Support Coordination has been done, and practice in other places,* identifies a more effective approach, if effectiveness is understood as inviting and supporting more people with ID/DD and their families into a self-directed lives as contributing members of their communities. Boundaries here define a life-included-in-community context that governs the publicly funded assistance specified and coordinated through the ISP. They focus attention on personally meaningful community roles that create a variety of good personal relationships between people with ID/DD and their fellow citizens. Attractors balance servicing the payment system with building trusting relationships that encourage self-direction and inclusion and co-creating supports to a meaningful home and community life. Over time attention to all three attractors generates tendencies that align more and more citizen energy and public investment with the experience of self-direction and inclusion.

* For a video example of the complex process of gathering, listening, planning, connecting and managing involved in strengthening a person's voice and creating new opportunities, see Life's a Journey goo.gl/jQwS8r

How Support Coordination can contribute to real change

A situation is **complex** when the people involved don't fully agree on a course of action and the way forward can't be decisively modeled with a linear, *A reliably causes B* logic. Consider integrated employment, the desired outcome of *Employment First* policy. There is real disagreement about what it is. Some say clients in a sheltered workshop are doing community integrated work; others (including us) that it is an individual job that mobilizes a person's capacities to make an economic contribution to a typical community business. There is disagreement about how many people will find it impossible to do an integrated job. Some say integrated employment is only possible for people who meet what seem to them common sense tests of readiness and that clients in day programs can't and will never pass those tests. Others point to advances in customized employment and refuse to rule anyone out before capable assistants have had a good try. There is disagreement about the benefits of work. Some see an unacceptable threat to benefit income and family stability; a risk of rejection, exploitation or abuse; and a loss of friendships and disability identity. Others appeal to positive stories and accumulating studies and point out that these are real but manageable risks and trade-offs.

This disagreement exists among people and families' as well as the service providers they count on. As long as people and their guardians are granted authority to choose qualified services that they believe best meet their needs, these disagreements will make a difference to the success of mandates like *Employment First*. A good decision process orchestrates acknowledgment and consideration of uncertainties about what is possible for a person, what their community can offer, and what available services can provide. These uncertainties can only be resolved by trying safe-fail tests. Uncertainty about a person's employability is most effectively resolved by joining capable assistants and actively searching for a job, that is, by moving into **complexity**.

In addition to disagreement about the feasibility of policies that promote inclusion and self-direction, there is another source of **complexity**. Communities that have substantial numbers of people with ID/DD successfully at work on community jobs have learned that supporting good jobs is an individual learning process. Practically useful understanding of a person's interests and abilities and the conditions of accommodation, technology and personal assistance that make the person successful at work emerges as people learn together with employers and co-workers what works and doesn't work for each person. Procedures like *Discovery*** guide inquiry in this complex domain. Others' learning can suggest good moves but the assistance each person needs to be successful at work emerges from the knowledge they create through action. This individualized process is as important for the 500th person in these communities who faces the choice to work as it is for the first.

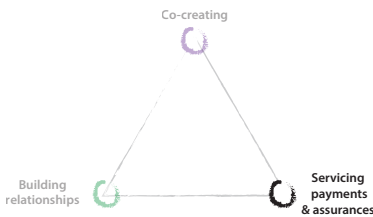
* While we recognize adult's right to decide their own life course even when it creates conflict with their family, many people's relationships are more complex than that, and so we refer to "people and families". A large proportion of adults with ID/DD count on their families for a place to live and a significant amount of assistance. Family members are a primary source of decision support for many more and often serve as legal guardians.

** marcgold.com and John O'Brien & Michael Callahan (2014). [Employment support as knowledge creation](#). *Research & Practice for Persons with Severe Disabilities* 35, 1-2, pp.31-38.

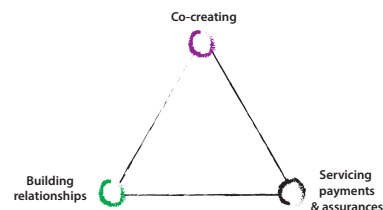


Administrative authorities assign Support Coordination responsibilities to support decision making. They define the work as providing information about available services, assuring that person centered plans are conducted in conformity with policy, maintaining as much assistance as possible by family members and friends and maximizing services from other agencies, preparing and negotiating an Individual Service Plan (ISP) with approved service providers, and monitoring and reporting performance on assurances that are a condition of funding (and, in some places, provisions of a court order or a court supervised settlement agreement). They may also be expected to advise on meeting requirements when people hire staff with Medicaid money and troubleshoot when services break down. People and families are due respectful and responsive performance of all these activities regardless of their choice of services.

It is possible to perform Support Coordination tasks as **ordered** transactions. These routinized duties can be discharged with a level of courtesy and competence that generates appreciation and positive satisfaction scores. In fact public authorities may encourage a customer service approach to the work. Support Coordinators may be enjoined to stick to a neutral “just the facts” form of providing information and forbidden by policy to advise or advocate for any particular source of support. Under this rule Support Coordination is neutral about what people choose –group home same as individualized supported living, day activity same as integrated work– as long as the choice correlates with an assessed need, fits within service definitions and can be satisfied within assigned funds. Sufficient information about the person to do the job of coordination can be captured on and picked up from computer screens. Conducting Support Coordination as a series of **ordered** transactions fades the attractors that make a difference to promoting inclusion and self-direction.



It is also possible to perform assigned tasks in the context of a relationship that engages **complexity** and allows Support Coordination to be an agent of real change. This involves noticing people and families who are at a point of transition and joining them in a way that promotes inclusion and self-direction. Conversation that opens possibilities and encourages people to action that probes limits is the medium of influence for Support Coordination. Making connections that bring others into the conversation multiplies assets. Focusing conversation on expressing gifts and dreams re-frames understanding and draws energy away from deficiency oriented services and toward mobilizing assets to create a desirable future in community. Facilitating problem solving reduces barriers.



There is variation among people with ID/DD and their families in their desire to work for community inclusion.

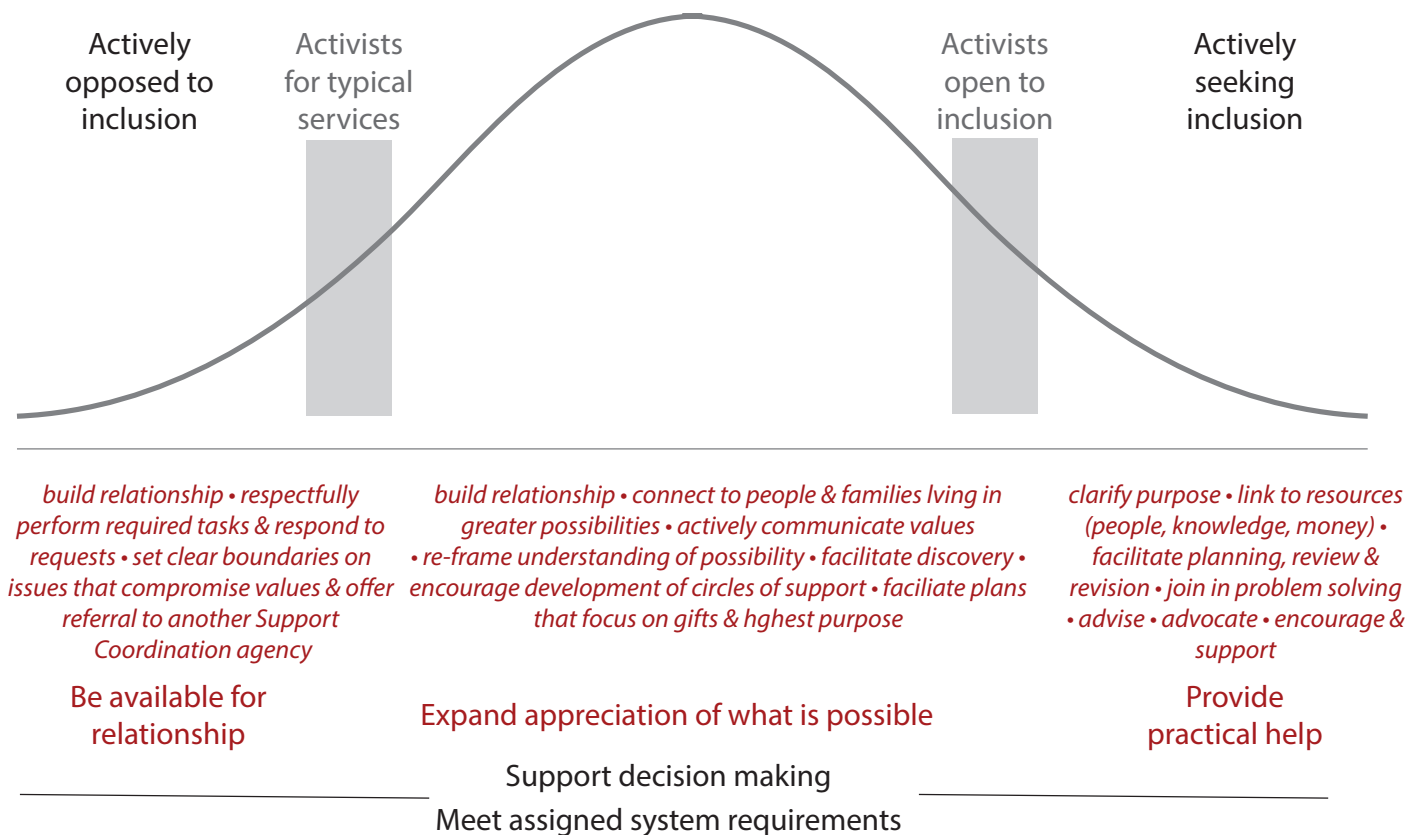
- Some people and families are **actively and thoughtfully opposed**. Integrated employment, civic involvement and life in one’s own home seem unrealistic or risky. They see bringing groups of people with ID/DD under capable supervision as the only reliable way to assure safety and protect against the pains of rejection. They use their energy and influence to resist policies like the *CMS Role*, especially when they see a threat to the services they use or want to use.

- At the other pole are people and families with an **active desire** to create pathways to contributing community roles for themselves and others.*
- Between these positions are many people and families who have had limited opportunities to consider the benefits of well supported inclusion. Many follow well traveled paths to day programs and group homes, or wait for the funding and vacant places necessary to follow these paths. Some are activists who lobby to expand typical services or founding day programs and group homes. Others direct their activism to pursuing inclusion.

These are not fixed positions. Over time, as trust grows, capable Support Coordination can shift more and more people and families toward an active search for inclusion.

To fulfill its assigned responsibilities, Support Coordination must meet the bottom line on the diagram below. This means processing plans that match assessed needs and individual preferences to appropriate services and define the goals that people with ID/DD will pursue. Assisting people and families to exercise more self-direction and search for opportunities for greater inclusion means moving beyond this bottom line. The band of red text on the diagram identifies some ways that Support Coordination can shift relationships into **complexity** by differentiating responses to fit people and families with different positions. Administrative decisions about the role and responsibilities of Support Coordination shape the space that is available for relationship building and co-creation.

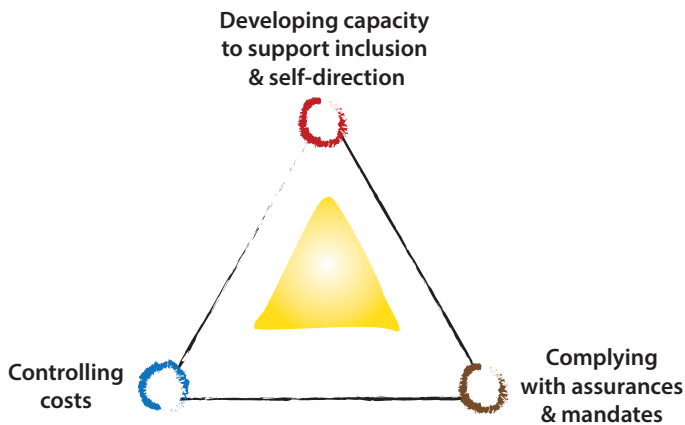
* For an exploration of people with ID/DD and their allies as social inventors, see John O'Brien & Beth Mount (2015). *Pathfinders: People with developmental disabilities and their allies building communities that work better for everyone*. [Inclusion Press](#)



A changing environment diminishes Support Coordination as a force for development

Support Coordination serves and is defined by the state administration responsible for services to people with DD. As a state increases its reliance on Federal Financial Participation through Home and Community Based (HCB) Medicaid Waivers, federal policy administered by the Center for Medicare and Medicaid Services (CMS) increases its influence on state plans and policy, and so on the structure and practice of Support Coordination.

Three attractors affect the administrative field of which Support Coordination is a part. To encourage the flexibility necessary for effective responses to different situations, capable administration allows a variety of ways to balance these three legitimate concerns.



- **Complying with assurances and mandates.** Concern to prevent abuse and neglect, avoid fraud, and provide adequate health services generates rules, policies and mandated processes (such as person centered planning) as well as monitoring, reporting and correction routines. HCB Waivers require states to make a variety of assurances and comply with rules by making and monitoring CMS approved plans for change. In some places Court Orders set priorities, specify action to implement and correct plans, and require progress reports. As well, there are state mandates and human service priorities, plans and policies.

- **Controlling costs.** Projected growth in Medicaid long-term care expenditures, driven primarily by increasing numbers of elders who become disabled, and a growing shortfall in meeting demand from the eligible DD population create scarcity. **Developing capacity to support inclusion and self-direction.**

Effective action to better support inclusion and self-direction –work that falls in the golden triangle on the diagram– calls for treating the situation as **complex**. Key actors may say the same words but disagree about current reality and what those words mean for the way forward. Some believe that most services have only technical adjustments to make because their clients are already included and in control, as evidenced by high scores on satisfaction surveys. As the box shows, others think that publicly funded ser-

Participants in a June 2016 workshop, which included a number of activist family members, identified these tendencies in publicly funded services...

- ... make the smallest investments necessary to keep as many people with ID/DD as possible living with and substantially assisted by family members for as long as possible.
- ... re-produce the congregation and segregation of people with ID/DD in settings that control people according to specifications set by service bureaucracy.
- ... dampen the effects of policies and programs that offer self-determination through control of an individual budget by imposing a growing number of limits and requirements on how people can use their budgets.
- ... reduce expectations by thinning, bureaucratizing and depersonalizing initially powerful ideas, structures and practices like self-determination, community living, integrated employment and person-centered planning.
- ... generate resistance among a minority of people, family members and staff who refuse to be trapped inside service control and so make spaces to support active citizenship and organize to challenge limits to inclusion and control.

VICES are currently organized to work against self-direction and inclusion. Investment in social invention is necessary to real progress. Employment First is a priority, and currently 3% of those enrolled in New Jersey's ID/DD adult services have an individual community job for pay.* Developing new pathways to work means figuring out how to create new relationships between people with ID/DD and employers. There is much to learn about how to control costs without violating the peoples rights. The mechanisms of managed medical care alone won't do; new and respectful ways to individualize supports to community living and mobilize family and community assets are essential to prudent public investment.

System administrators show a strong tendency to treat the capacity to support inclusion and self-direction as if it could develop in an **ordered** situation. (We think this is a result of skipping assessment of the situation and following a favorite pattern of top down linear approaches to change –the state **Cynefin** calls **disorder**.)

Consider the *CMS Settings* rule. Required change is mandated by a top-down cascade of detailed rules from CMS to state agencies to providers, modified to accommodate conflicting interests at every step of the way.** Continued funding is contingent on compliance. Required plans to implement the rule must be made in specified form, subject to public comment, revised and approved in response to review by higher authority. Plans must include a process for measuring, monitoring and reporting conformity to requirements and progress in meeting a series of projected milestones. Guidance, model policies, procedures and management tools reflecting assumptions about **best practice** in the design of services and the practice of person centered planning are disseminated through training and technical assistance Further training teaches how to manage the change process itself.

This command-and-control approach to change diminishes Support Coordination's contribution to real change. Support Coordination becomes responsible for correct implementation of person centered planning requirements and documentation of compliance with plans, assurances and procedures defined from the top down.*** This increases the focus on monitoring and reporting compliance by adding another element to track among the variety of assurances the state makes to CMS and the state rules that implement these assurance. The time and attention to detail required for compliance weakens the Development attractor: developmental work collapses into documenting compliance. Threatened consequences of inaccurate or delayed reporting matter to

*According to [StateData](#), New Jersey ranks 46th out of the states in employment for people with ID/DD. The US average is only 19%. However, five states have employment rates of 40% and above. That more is possible is clear. How to make significant progress must be discovered as it has been in places with more than ten times the rate of employment, by local people discovering together how to open paths to good community jobs.

** See the [Statewide Transition](#) web page maintained by the NJ Department of Human Services. Documents on this page demonstrate the extent of passionate disagreement about the implications of the Rule. For an extended discussion of this common **ordered** approach, see John O'Brien (2014) [Surviving Cogworld? Supporting people with developmental disabilities in a mechanistic system](#).

*** The practice of involving stakeholders in top-down planning can improve the words in the plans, but participants in such a process typically take on the perspective of top-down planners. They influence the conditions that authority will then impose on them as if the context could be effectively engaged as **ordered** simply because they have had a seat at the table.

In a complex situation:
 People have competing ideas about what is possible & what to do. *We discover the path by traveling together with purpose.*
 Shape **Emergent Practice**...
 ... Increase flexibility by setting wider boundaries.
 ... Make time & space for reflection.
 ... Try a variety of safe-to-fail experiments.
 ... Amplify what attracts the co-creation of good stories; dampen what attracts limits on possibility.

In an ordered situation
 It's apparent to those involved: *We've been here before & we know how to make this change*
 Respond with **best practice**.
 ... Make plans that commit to milestones.
 ... Define & apply metrics to monitor compliance.
 ... Look for efficiencies

people. When the funds to pay for needed assistance depend on accurate and timely interactions with computer screens, following the manual trumps discovery. Errors in reporting are treated as if they had the same effect on people's wellbeing as real life problems. Sluggish or glitchy IT services eat time and create frustration and anxiety. Support Coordinators justify attention to detail complexity by correctly pointing out, "It's what we have to do to get people (including ourselves) paid."

Dominance of prescription reduces the space to form the trusting, co-creative relationships necessary to individualize pathways to self-direction and inclusion. Person centered planning proceeds according to detailed, administratively defined protocols. Drop down menus and text boxes are assumed sufficient to capture people's dreams and aspirations for community life in a way that mobilizes action. Monitoring tools are assumed sufficient to capture the flow of people's lives in community in ways that stimulate imagination and creative action. Cost control efforts, such as a recent rule that restricts who people with self-directed budgets can purchase services, disrupt relationships that work. Support Coordinators must enforce these restrictions and have very little if any power to negotiate them. The expectation that Support Coordination will enforce the medical-model based belief that cost control demands tight, highly detailed service definitions that produce BIG DATA for analysis reduces flexibility and assigns Support Coordinators to say, "what you want is ineligible for funding."

The table on the next page contrasts the role and expectation of Support Coordination in two critical periods of system change in New Jersey from the perspective of families and Support Coordinators involved since the Self-Determination initiative. As they see it, in the first period, the Division of Developmental Disabilities (DDD), the responsible state agency, actively sought partnerships to explore self-direction and co-create individualized supports to valued roles in community life. People and families choose Self-Determination as an alternative to typical services and hired and paid a Support Broker to act as their agent in ways that were mutually agreed. Anyone who completed a short course of training could be chosen as a Support Broker and family members were encouraged to take on the role for other families. New forms of planning and organizing assistance were encouraged and novel expenditures were open to discussion with DDD representatives. In partnership with a DDD staff person, the person and Broker negotiated an individualized budget to follow the dreams and desires discovered through a person-centered plan made in a variety of ways customized to the person's situation. The structure was open to work in **complexity**. It's in this context that Neighbours, Inc. developed Support Coordination and support practices that promote inclusion and self direction.*

The current context seems to them considerably different and less friendly to working in **complexity**.** Support Coordination is necessary for a large and growing number of participants in publicly funded ID/DD services. Self-direction is one choice for administering available funds. Three-party partnerships negotiations engaging people and families and state representatives with Support Coordinators as people's agents to set

* For examples see the videos available at [Neighbours International](#).

** Support Coordination grew to assist substantially more people who chose self-direction in a middle context, from 2003 to the present. The details of this intermediate period are not relevant to the contrast we want to make here.

<p>Self-Determination (1997-2003) (Participants as of 2003 kept this arrangement until 2014)</p>	<p>Supports Waiver (2015–future)</p>
<ul style="list-style-type: none"> • Defined and managed as an innovation in creating supports. Brokers are active advisers, committed to values of individualization and inclusion. • A choice for people coming off the Community Services Waiting List. An available alternative to placement in a contracted residential setting that allows people and families to design and manage individualized supports, either on their own or in collaboration with an agency. • DDD acts as a committed partner with stakeholders. Broker defined as the person’s agent. • Very wide range of allowable expenditures. • Budget individually negotiated around the cost of the residential service the person would otherwise receive (Average = \$40,000 with considerable variation). • Budget negotiations involve person/family, Broker as a support to person/family voice and DDD staff member responsible to represent state’s interest. • Educational opportunities for people and families provided and encouraged. • People choose their Brokers, and have an individual contract with the Broker to define what their Broker would do. Sometimes brokers were active participants in co-initiating changes or un-sticking difficult situations. • Broker could be self-employed or employed by an agency. Up to \$4,000 per year for negotiated broker services including expected facilitation of a circle of support. • Choice of ways to plan depending on preference and situation. • ,Anyone who successfully competes required training can be a Broker. 	<ul style="list-style-type: none"> • State’s aim is to reduce waiting list in a way that controls costs and to prepare the way to move all DD services into managed care with other Medicaid funded services. • DDD’s plans to increase the number of people with Support Coordinators by 25,000 or more. • Support Coordination is system-wide. Each eligible participant will choose from among approved independent Support Coordination Agencies. An Agency assigned Support Coordinator prepares and monitors the Individual Plan of Care according to a process defined by DDD. • Support Coordinators are the face of the DDD system, responsible to assure fidelity to DDD policy and required practices. • Allocations are a function of the NJ CAT (NJ Comprehensive Assessment Tool) assessment. • Support Coordinators must assure that each expenditure in a plan is linked to a need defined by the NJ CAT and fits highly specified service definitions. • Support Coordinators must assure that DDD funds are “the last dollar”, i.e. no other public service or benefit or unpaid assistance is available. • Each plan must respond to the <i>Employment First</i> policy. • Tools for planning and monitoring are specified and required by DDD. On-time entry into defined templates is required. • Self-direction of services is an option, administered through a single DDD contracted Fiscal Intermediary. Service definitions determine what can be purchased and detailed reporting requirements must be met • Support Coordinators must meet formal education requirements.

budgets and design supports have been replaced by assigning responsibility to Support Coordination. Budgets are a function of acuity levels measured by NJ-CAT, a state developed instrument focused on enumerating deficiencies. Support Coordination represents the state administration and advocacy for participant’s interests is discouraged. Support Coordination informs participants of relevant rules and obligations to the state. It offers objective information about the full variety of qualified services, including group homes and day programs that congregate people. Participants have a choice among a large and growing number of approved Support Coordination agencies, though not necessarily of their Support Coordinator. Agencies can set boundaries on the area they serve and the total number of people they assist, but they must accept whoever chooses them. Support Coordination is defined as a professional role, open only to those who meet formal education requirements. The Support Coordinator’s

A parent who worked as a Support Broker remembers:
A few of the things I routinely did as a Broker, [especially for people with limited family support];

- *Staffing and Roommates - Recruiting, hiring, managing, firing.*
- *Housing - finding, leases, Section 8 assistance.*
- *Circles of Support - developing, facilitating, maintaining.*
- *Liaison with day programs.*
- *Hands on assistance with locating and managing medical needs, especially dentists.*

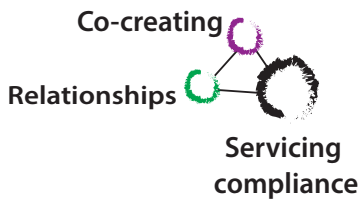
role is largely defined by state designed procedures that specify how plans will be made, reported and monitored. State definitions of services and conditions for self-direction impose tighter boundaries on services. The state's structure imagines Support Coordination as an **ordered** undertaking conducted as much as possible in **obvious** transactions constrained by a manual, required tools and data capture screens.

Possible futures

From the perspective of experienced Support Coordinators, administrative plans have changed the function and process of Support Coordination in ways that affect relationship building and the co-creation of self-directed supports to inclusion. These changes reduce the contribution that Support Coordinators can make to people and families choosing to discover individualized paths to community life. This increases the number of people whose power of choice dwindles to selecting the form of ID/DD group setting and staff control that will enclose them at the margin of community life. From the **Cynefin** point of view, these plans seem to assume that capacity to support inclusion and self-direction will develop when the situation is treated as if it were **ordered**.

Possible administrative futures. One future, perhaps the most probable in the short run, unfolds if administrators continue to reach for deep change with shallow methods: more exhortation about employment, inclusion and choice; more training and technical assistance; more guidance; more detailed rules; more (often ultimately unenforced) threats of penalty. Though this approach is most likely the result of administrators functioning in **disorder** (failing to step back and consider the nature of the situation and so implementing an habitual pattern), it results in approaching the situation as if it were **ordered**. This risks leaving the power to define inclusion and self-direction where it has been, in the inertia of common practice among dominant service providers. Reforms will result in improvements of life at the margin by meaningful but small refinements in practice: the average size of group residences will go down and people will have more privacy; people take outings to community events; a few more people will have jobs; people will share what is important to them with people they have chosen to participate in their annual person centered plan. Some people and families will continue to push the edges of possibility but their influence on typical practice will be small.

Administrators who tried on the **Cynefin** lens would have more options. They would have language to assess the situation in a way that reveals the importance of working in **complexity**. They would recognize the asset that those who want to push the edges of inclusion and self-direction represent and invest in partnership with them. They would allocate time and attention to searching, honest conversations with the people and families, community members, who constitute the living edge of inclusion and the service providers and Support Coordinators who assist them. They would make boundaries far more flexible for people and families who want to test new pathways to inclusion and self-direction. They would welcome and share in learning from tests of alternatives to existing procedures and thoughtful waivers of the form but not the intent of rules promulgated to safeguard people, protect the integrity of public investments, and measure and promote the values expressed in policy. They would develop multiple ways to amplify emerging practices that result in meaningful shifts in effective power and social position for people with ID/DD and their families.



It also makes sense to invest in trying different ways to make the most of the **complexity** available at the boundary between people and families, community life, and publicly funded services and supports. Reclaiming what worked during the Self-Determination period (see page 13) would provide a point of departure for a distinct form of Support Coordination modified to assist those people and families with a desire to develop new supports to self-direction and inclusion.*

- Offer a distinct form of Support Coordination dedicated to people and families who actively seek to push the limits of inclusion and self-direction.
- Expect active support for thoughtful and persistent effort to discover and mobilize local community assets.
- Provide a variety of ways for people to learn and expand their sense of what more is possible, including connections to other social inventors and opportunities for searching and challenging conversations.
- Give people and families the widest possible choice of who assists them. Expect that they will play an active role, encourage deeper understanding, join actively in problem solving, vigorously advocate for courageous action in pursuit of daring visions of inclusion and self-direction.
- Encourage creation of a new wave of supports to sustain self-direction life-long.
- Adopt an attitude of creative partnership that includes senior state administrators commitment to play an active, personal role and apply the greatest possible flexibility in interpretation (and potentially waiver or revision of) regulations and service definitions that inhibit inclusion and self-direction.

Possible agency futures. Consider Neighbours Inc, which has provided Support Coordination since the function was defined as a partner in self-determination. As part of a statewide effort to reform Medicaid, DDD has changed Neighbours' role, functions

* An example. Activist families and their allies in the Canadian Province of Ontario have co-created a distinctive form of assistance called Independent Facilitation. See oifn.ca especially David Hasbury (2017). *Weaving a Story of Change* and John O'Brien (2016) *Reflections on Changing Stories...Stories of Change*.

What guides Neighbours' work?

A person's dreams and goals

We respect each person's dreams... both the dreams and goals which already exist as well as new dreams which develop.

Control of resources

We believe in the ideals of self determination – the right all of us have, as adults, to be in charge of our own lives. We believe that people must have the opportunity to be in control of their budgets, staff, and homes.

Relationships

We believe that relationships form the foundation of our lives. We support people to stay connected to those who are important to them, and we facilitate new connections as desired.

Choices and responsibility

We support people in making choices and fulfilling the personal responsibilities that comes with the power of choice.

Contributions to the community

We believe that each person has something to offer to those people who are close to them as well as to the broader communities in which they live. We celebrate the gifts that each person has to offer and work towards turning those into valuable contributions to the lives of others.

Citizenship

We respect the citizenship of each person for whom we work. We seek to support them to be participating members of the communities they choose to live in.

and procedures (page 13). These changes challenge the agency's ability to follow its guiding principles. There is a bind here. People and families benefit from good information about substantial and continuing changes in the conditions of service provision, respectful help in complying with required procedures, and correct and timely submission of required documentation. Without this assistance they can't make good use of the Medicaid Waiver. People and families genuinely appreciate good information from Support Coordinators who understand their perspective and return their phone calls. However, paying the increasing transaction costs of Medicaid Waiver participation reduces opportunities to co-create meaningful community life experiences with people and families. This creative aspect of the work has engaged and sustained capable and experienced Support Coordinators, who feel its loss acutely. There is a risk that cognitive dissonance could bury drift away from Neighbours' guiding principles under the computer screen equivalent of huge piles of detail oriented paperwork.

At its best, Neighbours' Support Coordination is emotional intelligence in action serving social justice. A Support Coordinator who builds co-creative relationships comes to meet a person from an inner place of clarity about the value of inclusion and self-direction and comfort with the excitement and uncertainty of working together in **complexity**. Clarity about values energizes active curiosity about what more is possible in this person's life. It doesn't justify passing judgment on people and their families. Knowing this inner source of creativity and courage makes a Support Coordinator a generative listener, ready to partner in the effort to increase inclusion and strengthen self-direction.

Most of the **ordered** aspect of Support Coordination involves work with words. Interpreting administrative questions for people and families, gathering words from and about people, translating people's words about what they want from life and services into the language of Medicaid and transmitting them to service providers, putting the Medicaid words in their proper files, updating and revising them on schedule, sometimes arguing over them to justify a person's request for change or exception. Doing this work well is satisfying in that it smooths people's way in what can be an intimidating and complicated system. It also has clear end points and markers of achievement.

People vary in their comfort and attraction to working in **complexity**. Once they experience its benefits, many people who are temperamentally most comfortable with the predictability of **ordered** spaces find attraction to **complexity** stronger than their discomfort. Many people assume without thinking about it that their job will be **ordered** by some mix of job descriptions, policy and procedure manuals, and professional norms. If an organization chooses to grow to meet the growing need for Support Coordinators, it not only must invest in renewing needs to find ways for people to have an early experience of working in **complexity** so that their hearts know the possibilities that emerge when they bring that inner place of values clarity and comfort with **complexity** to their relationships with people and families.

As external pressure to do the work as if it were only **ordered** increases, the leadership challenged shared by everyone at Neighbours grows: **How do we sustain a culture that challenges us to apply our guiding principles by continually increasing our ability to co-create in complexity?** Practices that shape this culture are listed in the box on the left.

Working in **complexity** goes best when people...

- ... make time for deep and searching conversation, exploring both particular situations and the environments that shape them, surfacing different assumptions and readings of what is happening and what is possible.
- ... seek to understand the situation from multiple perspectives.
- ... acknowledge and move into places of conflict, uncertainty and stuckness in order to try something new.
- ... create probes that test assumptions about the state of the environment: what can be done and what cannot.
- ... establish boundaries that are flexible enough to encourage generation of many, different safe-to-fail experiments to discover new pathways.
- ... implement ways to amplify what works to establish a more desirable coherence between guiding purpose and action and dampen what doesn't work.

One step in sustaining culture that enacts Neighbours' principles is establishing the shared habit of applying the **Cynefin** framework to identify and make the most of opportunities to move into **complexity**. Two tendencies, reinforced by external imposition of change, reduce capacity to build a culture that supports work in **complexity**. Some react to what they experience as an invasive manipulation of their opportunities for contribution (and worse the lives of the people and families they assist). They want to **restore** a previous (maybe imagined) state when their work was **ordered** but ordered their way, by them. Others react with **over investment in order**. This can show-up as over-compliance, as if perfection in meeting requirements will open space for work in **complexity**. It can show up in unquestioned investments of time and energy in refining the plans, policies and forms that enforce order. These tendencies only become problematic if they sit unexamined instead of being seen as signals of a need to critically examine them and learn from **probes** designed to regulate loss and channel anger in ways that open new routes to good work.

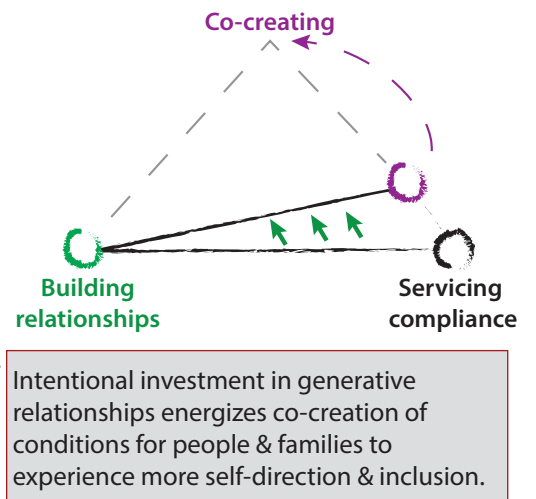
Support Coordinators will have more choices if they help each other recognize their role as, in itself, **complex**. Progress depends on convening and facilitating support circles and networks of families, but support coordination has typically been practiced one-to-one. There are conflicting demands and dealing with **ordered** tasks and **chaotic** breakdowns could consume the time and energy available. Their field of work is defined by significant disagreements about inclusion and self-direction. There is need for searching debate about what constitutes a **safe-fail probe**. Each week's schedule presents the opportunity to sort to-do's into **ordered**, **chaotic** (crisis) and **complex** decision domains and invest time and energy accordingly. Inventing effective ways to allocate attention and build skill in practices that support work in complexity calls for re-drawing boundaries and learning from probes into different structures and patterns of authority to hold the whole of the work.

This map of changing attractors outlines what resistance to being trapped in the **ordered** domain might look like. Intentionally building collaborative relationships with people and families who want to find paths to inclusion and self-direction increases the space for decisions and action that balance serving compliance with co-creating lives that exemplify Neighbours' guiding principles. The emerging results in the lives of people and families and their communities could, over time, strengthen the Co-creation attractor and increase ability to build more relationships that encourage inclusion and self-determination.

Moving into this future depends on Support Coordinators' the capacity to allocate time and energy to work in **complexity** while competently meeting increasing demands to perform the **ordered** tasks of servicing compliance and cleaning-up situations where administrative overconfidence in **obvious** procedures results in **chaos**.*

This work calls for regular, honest conversations across the agency about the costs of compliance driven compromises of guiding principles; assumptions what is possible given the state's requirements; and those aspects of emerging practice to amplify and those to discontinue If these conversations are successful, awareness of incoherence

* An example: a change in Fiscal Intermediary service provider managed as if **obvious** created multiple uncertainties and troubles for people who employ staff. Support Coordinators were on the front line of response for most of them.



Renewing the Spirit

Practices that encourage conservation of Neighbours' values as the Support Coordination role changes:

- Investment in safe-to-fail probes. Two teams have reorganized their work flow to discover ways to better incorporate family network facilitation and community building in their work.
- Community conversations. At about three month intervals staff who choose come together with invited local activists and resource people to focus on building more just and inclusive community. These conversations set role performance aside and attend to the context of the work: building a communities where all are welcome and each has opportunities to contribute their gifts. These conversations have encouraged a number of Support Coordinators to become more active in their own neighborhoods and communities in their role as citizens. Small grants from Neighbours have supported some local initiatives.
- Regular opportunities to learn graphic facilitation and the *PATH* and *MAPS* processes.
- Training in *The Art of Hosting*.
- Mentoring and coaching. Continuing relationships with board members and other practitioners committed to Neighbours' values give Neighbours staff access to expertise in Asset Based Community Development, ways to increase people's material assets, housing, leadership in innovation, community economic development, and neighborhood based organizing.
- Visits from critical friends.
- Learning journeys to local places of potential and national sites of innovation.

between values and action will generate tension. Holding the tension in a way that energizes the emergence of new possibilities is the test of leadership. Progress happens as the agency renegotiates internal boundaries and structures and invests in safe-to-fail tests of ways to amplify responses to the Co-creation attractor.

Intentional investment in working in **complexity** increases the odds that good possibilities will emerge, but there is no guarantee of success attached. Administrative plans and policies may enclose Support Coordination in performing **obvious** tasks to an extent that makes building co-creative relationships extremely difficult. This would make it necessary for those who want greater capacity to support inclusion and self-determination to find other means, outside the Support Coordination function, to mobilize people and families and support partnerships with providers of individualized supports

Support Coordination agencies like Neighbours, Inc. have not had time to discover the limits of their efforts to create space to work in **complexity** while competently doing the **ordered** work assigned them. State administrative partnership in agency efforts to create the conditions for work in **complexity** makes sense.

Possible futures for people and families. For more than 70 years organized families and their allies have been the source of beneficial innovation in policy and practice for people with ID/DD. As capacity developed and more allies chose to listen to and take direction from the voices of people with ID/DD, they themselves joined in leading efforts to push the edges of inclusion and self-direction.

People and families won't be able to live as they choose if they assume an **ordered** environment in which policy victories translate straightforwardly into real change. Not only are the possibilities for inclusion and self-direction unknown and discoverable only through co-creative action, but today there are multiple influences. There are far reaching attempts to control the growth of Medicaid by experiments in managed care. Providers defend their existing investments. Family voices speak for conflicting futures: some families are deeply invested in developing community opportunities and individualized supports; others advocate for village communities and other settings for special groups or place priority on treatment for defects and a search for cures inside people's disordered bodies.

Planning to implement the *Community Based Settings Rule* has created a forum to test the relative strength of these interests.* A probable future leaves plenty of room to keep doing more of the same with small changes. Those committed to a strong definition of

*For a record of this continuing controversy, see [Statewide Transition](#)

inclusion and self-determination will have to continue to organize, advocate and innovate to keep moving forward.*

People and families who reach past boundaries are the source of real social change. Their personal and collective effort to live inclusion and self-direction are essential to developing capacity to design and deliver good, sustainable support. Their journey will be facilitated under conditions that allow Support Coordination to work in **complexity** as partners.

* Ironically, pioneers of self-direction are burdened by accumulating rules and restrictions on their use of self-direction funds and the sheer lack of effective back-up supports to the extent that sustaining necessary assistance competes with the organizing and advocacy necessary to keep pushing the edges. Finding effective responses to this situation is a major opportunity for those interested in deep change.