

# What can we do with *those families*?

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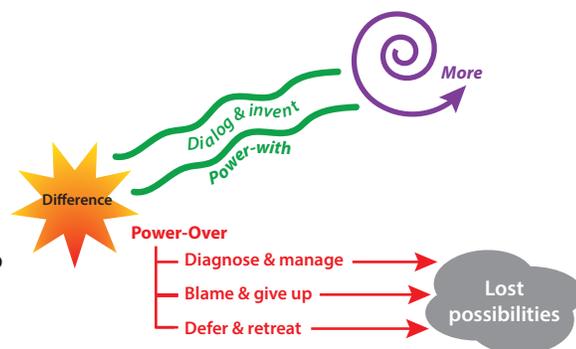
Discussions of person-centered planning among service workers sometimes turn to situations where family members take a position that conflicts with the worker's view of what is right for the person they are planning with and blocks action they see as desirable. Their belief about what is right may come from the person's expressed choice of something staff perceive as a right (dating or diet choices for example) or from staff knowledge of what could be possible for the person (living in one's own home or integrated employment for example).

We see four common paths branching from such a difference with family members. Three paths are expressions of power-over the person: **diagnose and manage** seeks to identify and remediate the family's perceived deficiencies of knowledge or attitude; **blame and give up** declares the family immovable and retreats from any change; and **defer and retreat**, delegates unquestioned power-over the person to the family. A fourth path, **dialogue and invent**, aims to strengthen power-with among all who care about the person, which is a fundamental purpose of person-centered planning. This path involves honest conversation that leads to agreed action that tests perceived limits of what is possible.

Power-over paths are undesirable. They encourage listening from a posture of blame and suspicion. They frame win-lose contests between right and wrong. They breed defensiveness, distance, and distrust as conflicting parties try to manage, motivate, and block others they judge to be compromising a person's rights, security, and future. They distort the person-centered planning process with dysfunctional rules that give the person the only legitimate voice in the process regardless of their need for others' active support. They result in frustration and resentment when people are silenced by polite avoidance or resignation. Disengagement deprives the person of the intelligence of multiple voices and the contributions of various gifts. The rewards of triumph over family objections can come at the cost of the support available from a circle of family and staff who have struggled to achieve a common vision and shared sense of how to move into it together.

The path of developing power-with is demanding. It depends on the planning group achieving and sustaining a level of listening that allows trust to grow and creative energy to flow. This way of listening to one another moves from defending current positions to take in new possibilities, discover others' experience and appreciate their perspective, and touch the highest potential in the current situation. Listening in this way engages the intelligences of multiple people's hearts, hands, and heads and so encourages action to discover new possibilities.

The path to power-with can be blocked by an unquestioned assumption that it is up to the family to go first in opening their minds and letting go of control, perhaps by following professional advice or submitting to training. This assumption goes with a common, reflexive diagnosis of families as "overprotective" when they question pro-



posals that staff see as progressive. Correcting this mistaken assumption begins when facilitators reflect, turning the beam of inquiry back on self.

Family experience does not begin with meeting one more new facilitator enthusiastic about another planning process. So this reflection will take thoughtful account of the wider history of common service and community responses to people with disabilities and their families, responses that may influence an encounter with a particular family in a planning session.

- Families may have been blamed for their children's impairments and lack of "progress".
- Families may have experienced rejection and shaming by members of the community they are now asked to trust with their family member. They have direct knowledge of the multiple consequences of the person's impairments and vulnerabilities when, as is too often the case, good support is missing.
- Families may have been given advice cloaked in professional authority that has proven unreliable or wrong or, on the other hand, inconsistent with what they are being asked to consent to now.
- Families may have been patronized with snap diagnoses and superficial advice ("You're grieving the loss of the perfect child" or "You just have to let go.") when family relationships are in fact complex and shaped by multi-generational histories.
- Many families have taken legal responsibility for substitute decision making, frequently on professional advice. They are legally obligated to decide based on their judgment of the person's best interest. The legal and practical mechanisms of supported decision making remain unfamiliar to many families, and indeed to much of the legal and service system.
- Families may have been let down and have good reasons to be skeptical about service system promises, especially in periods of austerity when new ideas might be covered for cuts to support. The change menu that service planners are promoting may be limited to service system agendas.
- Families may have seen many people come and go, not just those in formal roles but also those who profess friendship.
- Even more broadly, families, people with disabilities themselves, along with staff and community members live with the realities of social devaluation, expressed in social exclusion, assignment of people with disabilities to devalued roles as "Other", and imposed limitations on development. Everyone has work to do to become conscious of the workings of devaluation and embrace ways to intentionally resist.

This is not a catalog of despair but a prompt to respect the experiences that may shape family response to a proposed change that service workers favor. Many families have developed ways to understand these too common experiences that energize their search for the Good Life for their whole family.

Families are far from being the only source of resistance to change. Reflection will also focus the beam of inquiry on the capabilities of the service system that plan facilitators often represent. Structures incapable of delivering good support for valued roles in community life restrict options to join people on their journey toward the good things

in life and limit opportunities to turn conflicts into explorations of possibility. Family resistance –imagined or real– can become an excuse to avoid the hard work of structural change. Mindful facilitators will ask these questions of the systems that influence family life.

- Setting aside families with objections to change, how effectively does our system currently respond to the choices of people and families who are eager for more of the good things of community life? Can the system reliably deliver good integrated jobs that match a person's interests and capacities? How about access and support to live in a home of one's own, well supported and free from the regime of a group residence? Are alternative communication strategies, and technologies that support mobility, effective task performance, and health readily available when needed?
- How well does our system currently safeguard the people who rely on it? Does the system reliably encourage positive relationships and respond effectively to instances of disrespect, neglect, or abuse?
- Where new capabilities need to develop, how generously does our system support social invention, learning together by trying new ways to do new things?
- Has our organizational culture generalized from unexamined incidents of stuckness with some families to an unquestioned pessimism about the possibility of co-generating discovery of new futures? This shows up in readiness to drop families into an oppositional position and in overlooking opportunities to expand experiences of the Good Life where there is no family opposition.

The very way the system structures person centered planning may encourage a sense of impatient righteousness on the part of staff with no time to develop a trusting relationship, “We only have an hour for the meeting. How do we get ‘mom’ (sic, ick) to let him take the bus on his own?”\*

Honest reflection informs the inner state suited to the kind of listening that has the best chance to create relationships that can move into shared, creative action: humble, curious, compassionate, and courageous. Humble does not imply having no position to stand for in the conversation. It does encourage remembering not to assume authority and certainty in situations that call for person and family led discovery and social invention. It does suggest making the first effort to understand before expecting to be understood.

As service systems increasingly prescribe the way person-centered plans are done, it will sometimes be necessary to depart from standard procedure and reach back to the core of person-centered planning and build a vision of possibility through multiple more open conversations. When stepping outside official methods expresses the intention to build a power-with relationship, action to discover new possibilities has a chance to emerge.

This example of engaging family concerns from an internal place of starting with listening to find positive ways to journey together developed from stuckness in exploring a person's desire to move from a group home to a home of their own with individualized supports.

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\* Question from a workshop participant looking for a tool of persuasion to use on families. *Sic* is a standard way to designate an exact quote. *Ick* is my personal reaction to labeling parents with folksy appellations like “mom”

An approach that mobilized power with began with a simple ask of the family. That was to participate in conversation with no up-front commitments. This question, chosen with the family in mind, framed that conversation, “What if we were starting from scratch, with no services yet delivered, what might the best possible supports look like?” The purpose of this conversation was simply to practice deeper listening and see what pictures emerge.

In this more open space the voices of judgment (“she can’t do that”), cynicism (“nobody would rent to someone like her”), and fear (“what if...”) will almost surely weigh in to attempt to end the inquiry by pushing the participants into defensive postures. Welcoming these voices and better understanding the concerns and assumptions they signal keeps the conversation going. Several conversations opened space for discovery. The point was not to try to think away any potential difficulties or sell a guaranteed result. It was to practice respectful listening and exploration that shifts a future possibility from the realm of impossible dream into a shared space for identifying creative next steps and learning from taking them.

In explorations like this, one determinant of how many of these steps are actually taken is the degree to which service staff can be reliable allies. Organizational requirements that produce time pressures and restrict flexibility in planning conversations and following action work against the relationship building that leads to creative ways through differences.

A constructive relationship between service workers and families does not demand a promise to deliver success, too much is beyond direct control for that. It is often enough to deliver on a promise to walk with a person and their family as they together imagine and journey into a desirable future. Clarity about personal and organizational capacity to hold responsibility for this promise is essential to establishing right relationships and generating power-with people and families. Being in conflict about what is desirable can be a turning point in establishing right relationships.