

“I want the kind with the people and the pictures”¹

After a difficult start –institutionalized from age three to twenty-three in a place where “they treated us like animals”– Mike has composed a good life, taking many valued roles: husband, father, worker, home owner, friend, organizer, advocate, mentor, teacher, neighbor.² Anticipating the changes that come with aging, Mike requested funding for a person-centered plan from his case manager (a service option in his state). The case manager said that it was unnecessary for him to spend any of his budget on a plan because a new Federal Rule requires that Mike’s annual plan of care meeting be a person centered plan. Mike, who has participated in a number of person-centered plans organized through self-advocacy, asked some questions about the required plan and concluded, “I still want the kind with the people and the pictures.” Regulations that require a person centered plan as a condition of receiving Medicaid Waiver funds introduce a distinction between **Want-to-plans** and **Have-to-plans**. Each can make a positive contribution; both must creatively respond to constraints. A good **Want-to-plan** supports discovery of possibilities and life direction and mobilizes a person’s allies at important moments in their lives. A good **Have-to plan** gives a person effective control of the Medicaid waiver funded assistance they rely on. Committed and skilled facilitators with the time necessary to prepare and follow-up make a difference to the impact of both kinds of plan. How well either process works for for a person depends on conditions outside the planning process: the extent, diversity and resourcefulness of the person’s social network; the openness of the person’s community; the flexibility and responsiveness of providers of necessary assistance; the sufficiency of public funds for necessary assistance and the means for people to control those funds. Good plans will identify the current reality of these conditions and consider how to engage them.

Mike’s is a **want-to-plan**. At his initiative, he and his invited allies (the people) collaborate to create a customized process to address his desire to deal proactively with the new responsibilities and increasing impairments that show up with aging. Mike chose Michele, an experienced facilitator, to guide the process. Their agreement makes it clear that Michele is

¹ Thanks to Mike Raymond, Michele Lehosky and Alex Blanchard for their presentation of Mike’s plan at the *4th Washington State Community Summit* on 15 June 2016. These thoughts began in reflection on their powerful rendition of the continuing success of Mike’s person-centered plan.

² You can view Mike’s witness to growing up in an institution and a snapshot of his life today in this 2015 TV investigation into his state’s continuing operation of institutions: <http://www.king5.com/news/local/investigations/wash-decades-behind-in-serving-developmentally-disabled-1/48265785>

responsible for facilitating a process of change over time, not just a meeting.³ A graphic record (the pictures), created by Alex, provides an energizing memory of what emerges, a way to track and update action plans, and a way to orient new people to Mike's intentions.⁴ Occasional check-ins and revisions guide continuing action. One-to-one meetings assist Mike in sorting through all the suggestions and offers of help he receives to assure a good fit with who he is. Mike will bring some the information generated by this work to inform the required annual person centered support plan, but his **Want-to-Plan** does not substitute for it.

Mike's experience unfolds under highly favorable conditions for any person-centered plan. He has a strong desire to assure his wife and himself the best possible old age. Reciprocity for decades of generous neighborliness, concern for co-workers and leadership in advocacy give him a diverse network to call on. He is not inhibited in asking for help when he needs it. The help he needs is largely with navigating the unfamiliar territory of selling and buying property and preparing wills and other necessary documents and demands no change in his current paid services. Hard work and careful management has accumulated equity in family home. Many **Want-to-plans** will need to include provision for strengthening or establishing the social and material conditions for moving toward a desirable future.

Want-to-plans can also originate in a person's positive response to an invitation to join a process of organizational change. This sort of plan poses a challenge that an organization must stretch its capacities to meet.

Have-to-plans are a necessary step in determining expenditure of Medicaid funds on services to meet the assessed needs of eligible people. They are the final responsibility of system staff assigned to coordinate services. While the process can vary to accommodate a person's preferences, the process and resulting plan must comply with detailed standards. The New York OPWDD *Person Centered Planning Regulation Checklist* enumerates 23 requirements, 21 of which track US Federal Regulations.⁵

³ Other agreements might suit other circumstances. A different person might agree to fill the necessary follow up role.

⁴ Denigrating graphic records has become a cliché criticism of person-centered planning ("people have colorful pictures on their walls but their lives are unchanged"). Lack of commitment or capacity for creative action seem to me more likely causes of inaction than a vivid record of people's thinking does.

⁵ <http://www.opwdd.ny.gov/sites/default/files/documents/PCPChecklist.pdf> The 22nd standard, specific to New York, defines a person-centered planning process as a right and requires written notice of that right. The 23d assures that all relevant attachments are filed with the plan. The rule itself, *Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice (Section 1915(k) of the Act) and Home and Community-Based Services (HCBS) Waivers (Section 1915(c) of the Act)*, was published in the *Federal Register* on January 16, 2014.

Have-to-plans serve a worthy purpose. The rules set conditions for the person to direct the meeting, understand the results and assure that the person centered service plan documents the person's needs strengths, preferences, goals and appropriate services.

This checklist item, based on a Federal requirement, identifies the intended result of **Have-to-plans**:

2-5. The plan documents the necessary and appropriate services and supports that are based on the individual's preferences and needs and which will assist the person to achieve his/her identified goals. [Complies with CFR 441.301©(2) (v)]

This form of words sets **Have-to-plans** in the context of publicly funded disability services. Offering increased influence on which available provider(s) will serve a person and how those services will be of assistance is a clear benefit of **Have-to-plans** when there is a real choice among providers with a capacity to individualize supports.

This standard also locates a tension that constrains **Have-to-plans** as two impulses struggle with each other within the same sentence. One impulse, energized by commitment to self-direction and the development of people's strengths, expresses the life a person wants to live and the supports that they prefer to live that life. The other, tied to the historical anomaly of funding US disability support as if it were a medical service, aims to select necessary and appropriate services that are clearly linked to professionally assessed need. State policy can bias the struggle toward one impulse or the other. In some states⁶ the person centered plan is bracketed between an assessment of need that involves an extensive inventory of a person's deficiencies and writing an Individualized Service Plan (ISP) that must demonstrate a direct connection between assessed need and specified services and avoid public funding of "wants" or "lifestyle choices". Without the skillful facilitation of an intentional shift in perspective, a **Have-to-plan** will be primed by a focus on deficiencies and develop within unconscious boundaries set by judgements of what can realistically be funded.

A **Want-to-plan** can safeguard a **Have-to-plan**. A person and those who care can choose to create a space outside the world of disability services for conversation about a person's identity, gifts and capacities and the circumstances that offer the best life chances. Often, as with Mike, some action will result from this conversation that requires no change in publicly funded services. When the sort of changes in services that require a **Have-to-plan** are necessary, a person and their allies have a foundation for negotiating what they need from publicly funded services.

⁶ See for example, NJ Division of Developmental Disabilities (March 2016). *Supports Program Policies & Procedures Manual (Version 3.0)*.

Reflection

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Truly frame breaking change leading to lives that are valued require a process of unfolding. Even one session of facilitated conversation with graphics and hollow containers does not honor the unfolding quality of transformation of a life lived differently and in a more connected way. The realized **Want-to-plan** reflects a disciplined yet flexible process of poking at assumptions and uncovering new perspectives. It is, at its heart, relational. Therefore it is experienced as relationally complex, and ever unfolding (infinite).

Have-to-plans are regulatory at the center. They are detail complex and time bound (finite), transaction intensive, and time consuming and therefore distracting from discovery of paths to community. They move our attention away from people to systems of tracking compliance and coordinating production of services.

Much work and time go into assuring that **Want-to-plans** and **Have-to-plans** are complimentary. In most cases this objective lies at a conceptual level rather than an operational level. And not for attitudinal reasons.