

# Design Principles for Individualized Supports

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Cover image *Keys to Life*

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Chris recently retired after long tenure in the management of residential services for people with developmental disabilities in New York state. He has been tireless in inventing, implementing and sustaining individualized supports that assist people to assume valued roles in community life, beginning with the real choice of a good home that a person can genuinely call their own. Since his retirement he continues to share what he has learned with interested organizations.

You can read about some of what Chris and his partners at the Arc of Rensselaer County have achieved in *Keys to life*.<sup>\*</sup> Their collaborative accomplishments are the result of careful and creative person-centered design as well as persistent, assertive and skillful negotiation with a system of funding and regulation that imposes complex barriers to providing individualized supports.

Chris does not implement a model, he acts as a designer working in service of each person and their distinct situation. In this booklet he sets down design principles distilled from long experience. They are his minimum specifications for doing good person-centered work. Creatively and courageously following these principles offers the best chance of assisting people with developmental disabilities to have a good life at home.

—John O'Brien

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<sup>\*</sup> Beth Mount & Sandy VanEck (2010). *Keys to life: Creating customized homes for people with disabilities using individualized supports*. Troy, NY: The ARC of Rensselaer County. [keystolive@renarc.org](mailto:keystolive@renarc.org)

***Instead of an inflexible, hierarchical process that is designed once & executed many times, we must imagine how we might create highly flexible, constantly evolving systems in which each exchange between participants is an opportunity for empathy, insight, innovation, & implementation. Every interaction is a small opportunity to make that exchange more valuable to & meaningful for all participants.***

***–Tim Brown\****

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\*Tim Brown (2009) *Change by Design: How design thinking transforms organizations and inspires innovation*. New York: Harper Business.

The New York State Association of Community and Residential Agencies (NYSACRA), with the support of New York's Office for Persons with Developmental Disabilities, Developmental Disabilities Planning Council and Self Advocacy Association, has, over the past several years, sponsored four *Learning Institutes on Innovative and Individualized Supports*. Each Institute has had the participation of about ten provider organizations and has lasted between six and twelve months. Through a series of lectures, exercises, webinars and learning journeys to exemplary providers, participants revisit their mental models about supports for persons with I/DD and develop prototypes for change that represent their learning and advance the development of more individualized and self-directed supports.

During the most recent Learning Institute (June-November, 2015), I compiled a set of Service Design Principles to guide participants as they developed their prototypes.

These Design Principles apply to the design of individualized supports in any context, but my primary interest is in employing them to reinvest resources now bound up in congregate services in more individualized and self-directed supports.

–Chris Liuzzo

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## Get design questions in the right order

This is not so much a principle of design, but one of process. If the first questions are *how will we pay for it* and *what regulations will apply*, then the process will already be compromised.

Hank Bersani stressed how important it is to **not draw the bullseye** before the planning has even begun.

Of course, understanding who the people served are and what they may need in their lives is a primary source of guidance for service design. The measure of this should, at a minimum, be what most people consider the elements of a *good life* (page 8).

Start with the values you want to guide your design. Then, the other pieces will be begin to fall in place.

## **Increase the likelihood of persons attaining valued social roles.**

Successful supports result in the immediate attainment of a valued role: home owner or tenant, employee, club member. Just as important, it should set the stage for and increase the likelihood of people enacting other valued roles over time. One may move from being a tenant to becoming a valued neighbor, member of a tenants' association and a host of tenant get-togethers.

## **Honestly address vulnerabilities of concern, with careful attention to real vulnerabilities, not those projected onto people by human service systems.**

Real vulnerabilities are those which truly place the person at consequential existential risk of physical, social or developmental harm but for which insufficient compensating or offsetting intentional safeguards are not yet in place. These vulnerabilities of concern are identified by understanding and then addressing the primary sources of vulnerability, such as poverty, loneliness, the absence of voice and so on.

Human service systems tend to perseverate on low probability and often quite unspecific risks, such as fire, crime or general physical safety and on ostensible safeguarding interventions of low or questionable value and practical relevance, such as mandatory annual physicals, over staffing and over protection, filing of bureaucratic reports etc. While consideration of these risks and interventions have value, they are much more oriented to reducing the perceived risk and liability of the service provider. Intentional safeguards should not divert resources and attention away from more fundamental vulnerabilities of the people being supported and fool providers into thinking that they have adequately addressed real risk.

## Address real needs, not those invented by human service systems.

It is not difficult to identify fundamental human needs, which include love, friendship, safety, security, association, contribution, belonging, and so on. These are the things Wolf Wolfensberger calls *the good things in life*<sup>\*</sup> and what Aristotle and many others since call the *good life*.

Human service systems are not adept at addressing these needs but are skilled at inventing and occupying people in *working on* more superficial needs such as *needing* to keep one's room clean or learning to cook a meal or to make change of a dollar. Prioritizing these superficial needs amounts to a subtle form of coercion, requiring persons to address needs that are not really the person's priorities but distractions imposed by system routines and practices.

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<sup>\*</sup>For example, Wolf Wolfensberger, Susan Thomas & Guy Caruso (1996) [\*Some of the universal "good things of life"\*](#).

## **Decouple the supports provided to any one person from those provided to others.**

Many, probably most, support designs are predicated on resources (such as staff support) being shared by more than one person. A staff member may be required to visit numerous people in several apartment settings over the course of a work shift. In a group home, staff are constantly allocating their time among the people who live in the house.

Support designs should maximize the dedication of resources to a single individual such that the support one person receives is not dependent upon the supports provided to others.

Here is a simple test. You will know you are approaching satisfaction of this design principle when a person you support expresses a desire to go to a movie tonight and your answer is not *we'll see*, but *which show?* Patterns of resource use should reflect the priorities of the person not the most expedient way of staff managing their work.

## **Minimize social distancing & improve relationship.**

Typical staff-client relationships are tightly prescribed. Human service systems tend to impose strict social boundaries between recipient and provider by law, regulation, policy and procedure. Service disciplines, such as social work, counseling, nursing and so on, have long traditions of teaching boundary management as a process of keeping distance from *the client*. Yet at the same time, they teach about the importance of relationship itself.

While boundary management may have laudable objectives, such as role clarification and prevention of abuse, it inhibits, in fact, often forbids many authentic forms of bonding and connection between staff and clients and unwittingly promotes an “us and them” mentality.

Good design promotes an enriched quality of relationship between the persons in provider and recipient roles while ensuring the ethical conduct of supportive developmental rather than custodial relationships.

Good design promotes relationship between provider and recipient while insuring the physical and social safety of both.

## Promote & Nurture Right Relationship.

The concept of ethical partnering or *right relationship* is easy to intellectually understand yet profoundly difficult for humans to enact. It can be understood as the Golden Rule. If one simply started with the principle that people should relate to the people served honorably that would set the stage for much more ethical consciousness in how people are with others.

Many human services place little value or importance on *right relationship*, consciously and unconsciously. Treatment plans, service plans and behavior plans are replete with examples of providers identifying what service recipients should learn and do, in the eye of the provider. They are notoriously light on partnering, shared and respectful decision making, obligation, negotiation and mutuality. Good service designs disrupt this norm of indifference to ethical partnering and instead nurture the seeking of *right relationship*.

## **Minimize organizational and governmental intrusion while promoting transparency.**

Due to their reliance on other people for support and on public resources, people with disabilities experience bureaucratic intrusions most citizens would find invasive. For example, in regard to personal privacy, staff persons may have read their personal histories and know intimate details about them, often before even meeting them. Staff can often routinely impose demands, rules, sanctions and so on in an arbitrary manner. Clinicians decide what they will attempt to change about a person, sometimes even deciding that a person's inherent self needs modification (e.g. "so and so is too bossy with her housemates. We need a plan to address her bossiness."). This level of intrusion, manipulation and coercion is all too common and not recognized for how invasive and controlling it is.

Good service design is about thoughtfully balancing and resolving apparent contradictions. In this case, balancing transparency with the human needs for respect, privacy, autonomy and control is the designer's challenge.

## **Reinvest existing resources away from congregate services.**

We can expect little in the way of transformation from congregate to individualized services if we do not move resources from the congregate settings in which they are currently bound up to self directed individualized supports.

Absent intentional reinvestment, providers will continually seek new funds for individual supports while still maintaining congregate settings. It is better that there be a conscious decision to disassemble our congregate models and and thoughtfully replace them with *one person at a time* lives in the community that are suitably individualized in how they are supported.

## **Maximize control over use of resources and selection of support persons.**

There is a positive correlation between this principle and the others already identified. The more control people have over their resources, the more likely the other principles can be achieved. Even where people may need support with the control of these matters, the presence of support should not undermine the primacy of the person's own authority to direct their life and supports.

John O'Brien has written that part of our work is to *make hope palpable* for persons receiving supports. Control helps to do just that. Let us be sure to give people their lives back that they lost when they became clients.

## **Enhance the perception of persons with disabilities.**

Over 40 years ago, Wolfensberger identified the common role perceptions of devalued persons, including persons with disabilities. Among others these include the eternal child, the object of pity and the sub-human. He not only identified these perceptions but provided ample evidence of their universality.

Good service designers are conscious of the danger of these negative role perceptions and are intentional about addressing them by emphasizing and nurturing normative perceptions of people to counter this danger

## Be flexible to change with changing needs.

Standardized or *fixed* service models and practices, such as group homes and day programs do not have sufficient flexibility to change with a person's changing wants and needs as do "stand alone" self directed individualized arrangements. They are, by design, fatally inflexible. If a person's needs change, there are two typical responses...

... fix the person so that the standardized model can continue to be employed or

... move the person to another standardized model ostensibly designed to address this new need (think, *medically frail house* or *behavioral house*).

In contrast, quality service design results in resources that can be shaped and reshaped around a person as his or her needs change over time without recourse to disrupting adaptive social and physical environments. Resources can be thought of as akin to the Gumby toy: able to move and bend with a person. This flexibility must arise not only from new models and structures but from an ethic and attitude of committed responsiveness.

## **Be efficient.**

The current human service system expends an almost unimaginable amount of resources while achieving relatively little in the way of meaningful outcomes.

And, there are little, if any, data demonstrating that congregate services provide the elusive economy of scale so sought after by planners and managers.

With attention to good design principles, it is possible to spend resources more wisely, achieve better outcomes and to reinvest away from segregation and congregation.

## **Author's Note**

These principles are not presented as exhaustive.

I offer profound appreciation and gratitude to many others who have influenced my thinking over many years, including Wolf Wolfensberger, Hank Bersani, John O'Brien, Beth Mount, Michael Kendrick, Tom Nerney, Derrick Dufresne, Mike Mayer, and David Pitonyak. Their thoughts and contributions are evident throughout the principles.

**Support valued social roles**

**Address real vulnerabilities**

**Address real needs**

**Individualize supports**

**Minimize social distancing**

**Promote right relationship**

**Minimize intrusion**

**Reinvest**

**Maximize the person's control**

**Enhance perception of the person**

**Be flexible**

**Be efficient**