Noticing We’re Upside Down

Avoiding Misperceptions When Designing Supports

John O’Brien

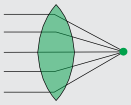
Design depends largely on constraints.
–Charles Eames

People with intellectual and developmental disabilities (ID/DD) have better lives when the supports they need are intentionally designed to fit their distinct inter- ests, capacities, and impairments.. Supports will fit better when the design process –known as person-centered planning to the field – recognizes and works to satisfy multiple constraints[1] rather than shrinking the focus to fitting the person into a predetermined program. Some constraints define purpose others limits. Some must be chosen, others impose whether desired or not.

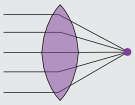
Constraints that serve purpose

To serve its purpose, good person-centered planning accepts the seven interrelated constraints summarized here under the designer’s favored phrase, *How might we…?*.[2] These seven lenses open a search for possibilities in the life of a particular person in their local neighborhood and community. The aim is a design that honors these seven constraints as much as possible while engaging more obvious constraints such as funding supports, negotiating com-munity access and accommodation,

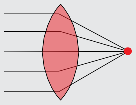
How might we…?



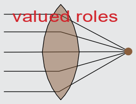
…increase knowledge of, & personal connections to, oppor- tunities to participate in & contribute to improving neighbor-hood & community life.



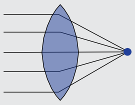
…strengthen existing relationships, organize mutual support, &diversify personal networks.

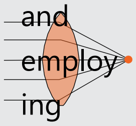


…establish & safeguard roles that attract respect, express gifts & capacities, encourage development, & offer membership opportunities for

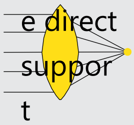


…respect & actively support autonomy & self-organization through deep listening, dismantling structures & habits that





and employing capable direct support workers.



promote inequality, & intentionally organizing individualized support for decision making.

...mindfully consider risks & vulnerabilities specific to this initiative, identify protective factors, & establish the conditions that will support & develop individual & group resilience.

...intentionally connect with the sense of highest purpose in all those involved; call to each person’s gifts & passion.

commitment

inner journey

...make space & time to establish ways to sense what more is possible, let go of judgment, cynicism & fear enough to be touched by the future that wants to be born, & prototype to learn ways to bring that future into being.

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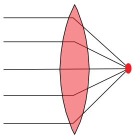
1 Constraints are the conditions a design has to satisfy in order to fulfill its purpose. Constraints form a system: each affects and is affected by the others. Some constraints are imposed externally, like system regulations, some are embraced voluntarily, like those in the next column.
For a good introduction see Tim Brown (2019). *Change by design*.

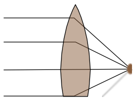
2 IDEO Design Kit www.designkit.org/

The original list of these lenses was created by a team of participants in the Pres-encing Institute’s 2021 *U.Lab 2x: Accelerator for Systems Transformation* most of whom are associated with Pathfinding Outfitters.

Each of these purpose related constraints can be thought of as a lens that focuses attention on a dimension of good support. They clarify good questions that encourage social invention rather than yielding answers. Intentionally viewing and shaping an emerging person-centered plan from each perspective improves individual supports and informs organizational and service system development.

What would it take to see more?

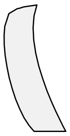




Lenses focused on purpose stimulate imagination and discovery among the planning circle that holds the person at its center. When the view through a lens reveals a person contributing their gifts to the common good of friends, family, or neighborhood, the circle asks what it would take to see those gifts mattering even more. When the view through a lens reveals a person whose gifts remain hidden, the circle asks what it would take to call a contribution forward. When the view through a lens reveals a person with a measure of autonomy, the circle asks what it would take to see the person exercising even more control of their life. When the view through a lens reveals a situation where others enforce power-over the person, the circle asks what it would take to see others exercising power-with the person.

Upside down lenses

Prism lenses can turn the world upside down.



Some lenses clarify sight. Others turn the world upside down. A series of psychology experiments conducted in the 1890s employed prism glasses to investigate perception. These experiments, and many following, demonstrated adaptation: after a period of unpleasant disorientation subjects began to see the upside down world the lenses continued to deliver to their eyes as right side up.

This idea –that we have the capacity to adapt to see an upside down view of the world as normal– extends the lens metaphor to include a number of common misperceptions that powerfully affect the lives of people with ID/DD and shape the context for person-centered work. When taken for granted these distorting perspectives dim imagination. Discovering what more is possible for a person and inventing the supports to take the next steps into possibility are overshadowed. Noticing and naming these constraints and the ways they obscure the vision of a whole developing person opens the way to creative resistance.

A way of seeing is also a way of not seeing.

–Kenneth Burke

These distorting lenses make sense of the situation of people with ID/DD, but more harmfully than helpfully. People with ID/DD do live with differences in body, brain, and mind that can impair their participation without good support, but it is devaluing interpretations of those differences that produces social exclusion.

Through these lenses, ID/DD appears as a source of differences that make a person show up as “other”, one of “them” rather than one of “us”, permanently deficient in what is necessary to claim full citizenship because of their abnormal body, mind, and behavior, excused from responsibility by incompetence and so in need of con- stant supervision, a burden or danger to family and community. They do their work by framing differences as defects and amplifying attention to these defects until they define the person. Through these lenses social exclusion and restrictive control are natural consequences of the person’s deficiencies. People planning services can dismiss the seven “How might we…” challenges to segregation, congregation, and restriction. Distortions blunt the ability to even imagine a good life as an engaged and contributing citizen and feed the notion that people with ID/DD are best off with “their own kind” in special settings overseen by specialists.

Wolf Wolfensberger named a set of distorting perspectives in *The Origin and Nature of Our Institutional Models*[3] (listed to the right). He saw these misperceptions as selffulfilling prophecies, reasoning from history that the way people with ID/DD show up in a societies’ imagination strongly influences the expectations they experience, the nature and form of the supports they are offered, how they develop, and so their chances of living as a valued citizen. Once these ways of seeing people with ID/DD and the structures and practices they entail come into the light their influence can be countered. Some of these perceptions have diminished in influence, others remain influential, still others have acquired new variations in a changing society.

Eternal child

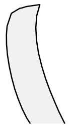
This persistent lens interprets different rates of development and the need for accommodation and highly skilled instruction as signs that the person will remain a child forever. Rendering test scores as mental age encourages limiting statements like this one, “He has the mind of a five year old in a 30 year old body.” This unfortunate interpretation turns differences into limits. Banishing the perspective won’t magically erase differences in development and difficulties in learning, but setting aside the lens and the sense of certainty it brings opens space for new possibilities to emerge.

- Discarding the pessimistic belief that a person’s past rate of development or need for accommodation imposes an impenetrable ceiling on a person’s future potential opens space to customize opportunities, accommodations, and supports to open age-appropriate opportunities. This is particularly important for people seen as infantile (“She has the mind of a six month old”) who may even be denied access to opportunities to experience skilled and committed efforts to establish communication.
- Those who assist a person are easily triggered to take a parental posture with eternal children. Understanding the person as if they were a child in need of discipline and protection legitimates enforcing power-over a person. Undermining this foundation of parentalism opens the way to development of more respectful relationships in which people could discover power-with one another.
- Noticing the distorting effects of looking through the eternal child lens interrupts the practice of reflexively imposing legal guardianship and makes room to explore and possibly adopt alternative forms of decision support.
- Sensitivity to the error of projecting images of eternal childhood encourages a reach for age-appropriate substitutes for spectacles like charity sponsored imitation high school proms held mid-afternoon for groups of mature adults.

Subhuman Organism Menace

Unspeakable Object of Dread Object of Pity

Object of Charity Holy Innocent Diseased Organism Object of Ridicule Eternal Child



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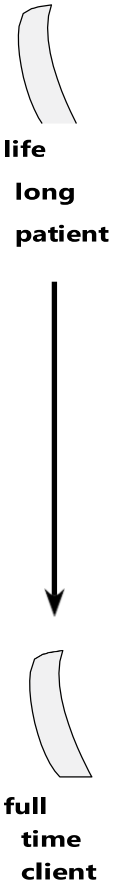
[3] This book is out of print and hard to find, but still worth careful study. The most available version is the first, published in 1969 as a chapter in *Changing Patterns in Residential Services for the Mentally Retarded* and available for free download from the Disability History Museum. The list is the version that appears in Wolf Wolfensberger (1972). *The Principle of Normalization*. Language alert: these documents use labels common at the time.

Patient – Client



From their beginnings in the mid-19th century and for the following century, publicly funded services to people with ID/DD were almost all superintended by physicians and organized by a nursing hierarchy. The intention was to harness professional knowledge to provide a better place for those they labeled than any family or community could offer. Those in authority claimed ownership of the diagnosis and treatment of the differences in body, mind, and behavior that they labeled mental deficiency. They sought delegation of complete responsibility and control from families, communities, and other services available to citizens. They offered a total regime of supervision and care that made people full time, usually life-long, patients whose every moment was overseen and guided by professionals who acted through staff who were often dressed in white well into the 1950s. In most instances good intentions were overwhelmed by insufficient public investment, overcrowding, and drifting institutional missions. Those who were more capable did most of the work of operating the institution. Those with more significant impairments too often suffered an almost indescribable level of neglect and short lives.[4]

Court decrees, exposés, human rights advocacy, debate over guiding values, research into new interventions, social innovations, and periods of legislative interest have reshaped services. State operated institutions account for a shrinking proportion of services. The medical-nursing hierarchy has been repopulated by people from diverse backgrounds, including many from outside traditional professions.
The focus on community life, including employment, has grown. More people are supported in their own homes.

Two threads run from the founding of institutions until today. One thread carries the belief that people with ID/DD will live their best lives inside professionally designed and operated programs, as full time clients.[5] Trusted programs are building based with professionals in charge. The second thread carries the invitation (or requirement) to delegate responsibility for the person to the system of ID/DD services. The system lifts the burden of care from family, community, and other human services. Agents of the service system hold authority to define need, guide goal formation, and assign services. As well they are mandated to involve the person (and family) in planning. Staff are responsible for implementing a professionally approved routine of activities that meet assessed need. Advocacy focuses on protecting and increasing investment in availability and quality of programs. Many families search for programs to trust with their disabled family member's future and some undertake to found and administer them.

At first glance, the ideas that support comes through enrollment in professionally designed and managed programs and that many families search for programs they

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[4] See Michael D'Antonio (2004) *The State Boys' Rebellion* for an account of institutional life for more capable patients. Burton Blatt (1966) made the neglect of those more severely impaired visible in *Christmas in Purgatory,* a shocking photographic essay that energized reform (view in The Disability History Museum).

[5] "Client" derives from Latin through medieval French. It describes a feudal relationship in which a weaker party defers to the will of a stronger party in return for protection. This is the form of dependency intended here.

can trust with their future may seem trivial, a glimpse of the obvious. However, noticing and suspending what has been taken for granted opens more space for social inventions guided by the *How might we...?* lenses.

- Suspending the idea that good support begins with placement in predetermined programs allows an individually grounded process for developing support to develop and take root. Committed and creative people have demonstrated that this start-with-the-person design process works.[6]
    1. Discover enough the person's interests, gifts, capacities, and sense of purpose to inform the first steps of a search for community roles.
    2. Identify and connect with valued roles in the person's neighborhood and community that allow expression and development of those discoveries (e.g. householder, life sharer, member, employee, activist, entrepreneur).
    3. Design and organize the set of accommodations, enabling technologies, personal assistance, and individual safeguards that will best support the person in valued community roles and places. Consult professionals with expertise in support for impairments in communication, mobility, self-regulation, learning, and health for advice, education, and support as needed. For people who live with their families, recognize that supports for community roles must include accommodations for the whole family, such as taking account of family work obligations when scheduling necessary support.
    4. Regularly update knowledge of the person and renew the sense of what more is possible. Seek new social roles and adjust supports as situations change.
- The shift from delegation to programs to co-creation of supports for valued community roles strengthens the voice of people with IDDD and their allies and increases their responsibilities. This generates demand for a variety of learning opportunities that broaden the sense of what more is possible and increase practical understanding of the *How might we...?* lenses.
- Moving away from placement in programs does not imply unleashing anarchy. Good lives for people with ID/DD depend on availability of trustworthy, committed, and competent support workers, professionals with expertise in effective responses to impairments willing to join in co-creating supports, and partners in accessing valued community roles and designing and re-designing supports. Inventing a variety of effective ways to organize these necessities is a worthy challenge. Creating local ecosystems of support for co-creating access and support offers community organizers meaningful work.
- Overturning the policies and practices that uphold program placement and delegation is the next frontier in deinstitutionalization. Undoing the

muddle created by funding supports for community life as if they were means tested medical treatments calls for imaginative and persistent advocacy.

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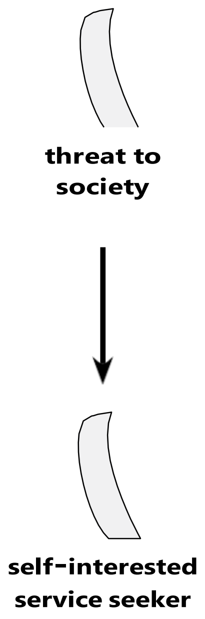
[6] See John O'Brien & Beth Mount (2015). *Pathfinders: People with Developmental Disabilities & Their Allies Building Communities that Work Better for Everybody.* *inclusion.com and Hanns Meissner (2013). Creating Blue Space: Fostering Innovative Support Practices for People with Developmental Disabilities. inclusion.com.*

Threat to society: eugenic to economic



Early in the last century, enthusiasm for eugenics as the key to social progress shaped a lens that revealed "hereditary feeble mindedness" as the runaway cause of a rising tide of all forms of "social degeneracy" from alcohol abuse to idleness and leaning on public welfare. Reducing a whole person to one of a horde with a mindless, promiscuous drive to broadcast defective genes defined a menace that threatened the whole society. This lent considerable energy to the expansion of institutions to surveil, segregate, and sterilize people with cognitive impairments and fed an anxiety about intellectually disabled people's sexuality that lingers until today.

The 21st Century manifestation of this perspective lumps people with ID/DD together with elders and others who require long term support and defines their growing numbers as a collective threat to the public purse. Rising numbers, increasing need for assistance, changing demographics, and a workforce crisis that foretells growing labor costs predict a significant increase in the proportion of GDP invested in long term support.

The neo-liberal ideology currently influential in public policy sees it as rational for people and families to act in their self-interest and accumulate as much publicly funded service as they can get. This sets person-centered planning in the context of an economic game where the state aims to discipline demand as the recipient maneuvers to capture as many service dollars as possible. Stringent eligibility requirements. Strict and narrow service definitions. Demand for plans that tightly link services to externally assessed need and evidence based practice. Procedures to differentiate "needs", which are eligible for funding, from "wants", which are not. Time and task measures that specify and control services often in 15 minute increments. Close audits. Value based contracts with payment contingent on system defined outcomes. Care management structures that shift risk away from governments. Black-box actuarial models that validate the impersonal rationing of public funds.

These practices push decision making away from negotiation among collaborators and toward algorithms driven by objective data from standardized procedures. The idea of support shifts toward a set of transactions rather than an artful form of human relationship. Direct Support Workers become interchangeable parts.

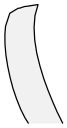
The current trend that wraps responsibility for person-centered planning into the system of cost controls complicates navigation of this bureaucratic territory. Those who aim to use public funds in person-centered ways have to figure out ways to adapt to the rising influence that view through this lens has on the context for person-centered work.

- People with ID/DD and their allies need to recognize that, in the context of cost containment, system provided person-centered planning will be limited in its capacity for discovery and social invention. System embedded person-centered planning can deliver funding for services and assist in a making good match between person and service provider. Informing system sponsored planning with deeper sense of what more is possible for the person goes better when people with ID/DD have an independent circle of support who can invest in independent planning and action.

- People with ID/DD and families can support and coach one another. Joining one another in individual planning and advocacy for a more capable system multi- plies power.
- Provider organizations can creatively support the use of whatever form of self-di- rected services a system allows. There are opportunities to serve and learn in offering a choice of supports such as service brokerage, community guides, help with personnel and administrative matters, back-up if supports break down, crisis support, and skilled assistance to locate housing.
- Providers can organize their work as discovery and the creation of valued social roles and purchasers of service can create channels to pay for it. Customized Employment is a good current example of this adaptation.[7]

Better off dead

People with ID/DD have achieved so much that its possible to overlook a lens that produces a dire and dangerous understanding of people with ID/DD. That is the notion that disability imposes such suffering and burden that a person would be better off dead.



Sometimes people with disabilities advocate for policies that give them access to a choice of medical assistance in dying as a right.[8] Sometimes medical practitioners act as if a disabled life is of lesser value: Do Not Resuscitate orders may be imposed on people with ID/DD as a matter of course; psychoactive medications are over-pre-scribed; routine medical checks are neglected; the voices of family and support workers with expertise in a person's medical history are ignored.[9] Other expressions of this view are structural. The widespread availability of a form prenatal testing that would allow the virtual elimination of people with Down Syndrome makes this perspective public.[10] Otherwise hidden structures show up by inquiring into the multiple causes of significantly diminished life expectancy for people with ID/ DD,[11] some of which will be found in health system neglect and others in the social determinants of health.[12]

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7 See Marc Gold & Associates *What is Customized Employment?* www.marcgold.com/what-is-customized-employment

8 Canadians face this as political issue around establishing safeguards for Medical Assis-tance in Dying. inclusionalberta.org/maid/

9 For an example of an appropriately intense response , learn about The Medical Safequards Project (medicalsafeguarding.org). This initiative provides consultation for heath enhance- ment as well as safeguarding for people in heath care settings.

10 The issues raised by prenatal testing are explored in Sarah Zhang (2020). The Last Chil-dren of Down Syndrome. *The Atlantic* bit.ly/3wzr8tp

11 *Stop People Dying Too Young* (bit.ly/2QSv6Ou) is a group of people with ID/DD and family members in the North of England who are exploring reasons for and responses to dimin- ished life expectancy. Among other matters, they have made a public issue of the common practice of physicians identifying ID/DD as cause of death and the

failure of coroners to conduct inquests into deaths where medical neglect is a potential cause..

12 Social determinants of health are social and economic conditions that drive health out- comes, They include many factors outside health care, particularly the distribution of power, money, and resources. Unfair distribution, which disadvantages many people with ID/DD, creates avoidable health equalities. Michael Marmot (2015) *The Health Gap: The Challenge of an Unequal World*.

This lethal perspective generates a current that pollutes the social context for people with ID/DD. Mindful resistance is essential.

- Safeguarding interactions with health care, especially hospital stays, is vital. Seek medical professionals who see beyond ‘better off dead”. Making it clear that their patient is valued as a whole person by the way others are present and share knowledge of the person makes a difference. Building relationships with medical and nursing staff that provides a foundation when assertive questioning and advocacy for the person’s wellbeing becomes necessary is necessary.
- Those people with ID/DD and family members with a gift for communication can contribute to the education of practitioners as more professional schools make space in their curriculum for the views of disabled people and their families.
- Consider engagement in the political debate over prevention measures like genetic screening and policy positions that hold disability alone as a sufficient reason to give a disabled person access to choose medical assistance to die. These are highly charged, complex issues; all the more reason for people with ID/DD and their families and allies to take an interest and raise their voices.

Community
Relationship
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Roles
Power-with
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In the long term

In the long term it is a steady increase in number and variety of people with ID/DD who show up in valued community roles that offers the best possibilities for reducing the limiting influence of these upside down perspectives. By noticing and naming the effects and source of upside down thinking and purposefully embracing the *How might we…?* constraints, person-centered planners can liberate the imagination that activates meaningful journeys toward good lives in more just and inclusive communities.