

Walking Out Walking On

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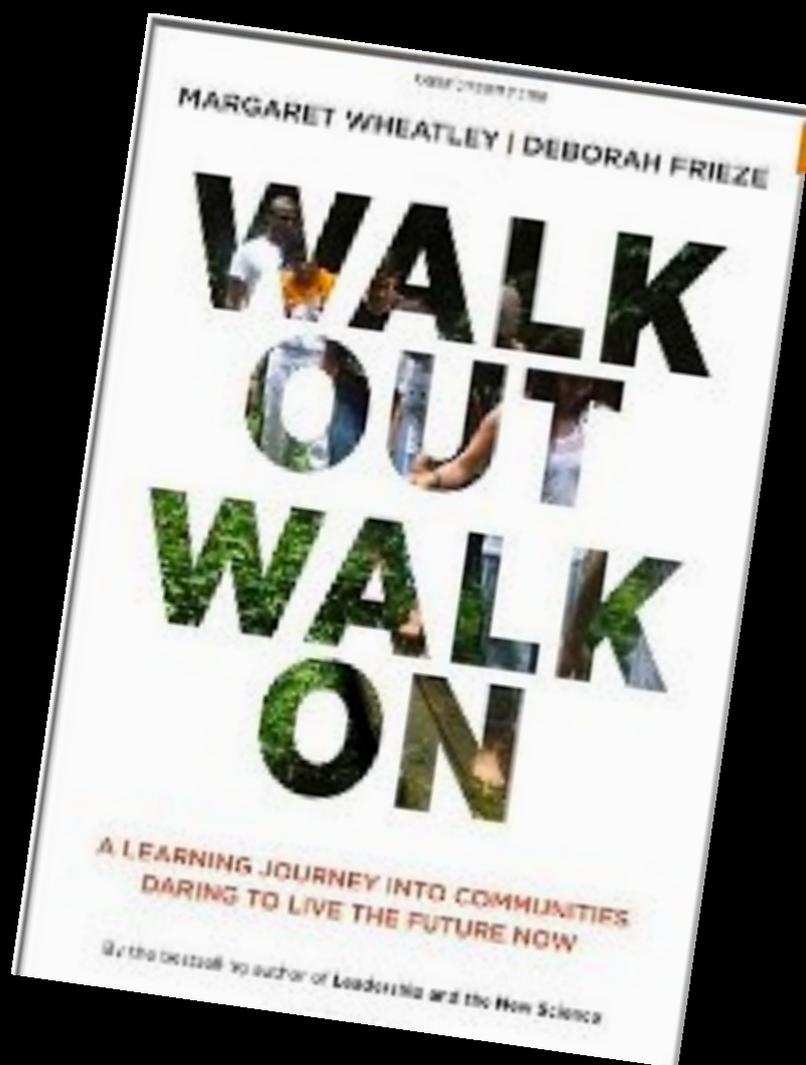
John O'Brien

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I have claimed the privilege given legislators to “revise & extend my remarks in the record.” There are notes on many of the slides that are a further attempt to say what I mean. Unless we understand & create space to live beyond the limits imposed on our actions between the mismatch between the work of social inclusion and the taken for granted ways that we organize our systems, we will remain frustrated with the results of our advocacy. I'd welcome any comments or criticisms.



Step 1: Claim your own name to hold your purpose



Dropouts

Walk Outs

There have been several incisive and important critiques intended to influence the implementation of the act. I can't add much to them; I want to step back and look at how the mental models that seem to shape implementation lead to significant mismatches between what's required to do the work of social inclusion & how the system is "transforming" itself.

...Promote **the** Social Inclusion

Oddly, the Act's title makes it seem as if social inclusion about something done to/for "them" --reproducing the problem it wants to solve. It makes more sense to see social inclusion as an emergent characteristic of a whole community when it follows practices of hospitality accommodation & gift exchange. The Act can't achieve its purposes without consciousness born of reflection.



About The Services and Supports to
Promote the Social Inclusion of Persons
with Developmental Disabilities Act, 2008

“Today, many things indicate that we are going through a transitional period, when it seems that something is on the way out and something else is painfully being born. It is as if something were crumbling, decaying, and exhausting itself –while something else, still indistinct, were rising from the rubble.”

–Vaclav Havel



Culturally & socially we are struggling with a misfit between the work & learning we need to do to have a just & sustainable economy & an inhabitable planet and the taken for granted social forms we rely on to organize ourselves. The Act & its related policies are an instance of this misfit.

For at least two generations, families have been the socially invisible resource that allows the visible system to function.

Mismatch between modes of organizing & what it takes to do the work can make for ironic effects of political: words accepted at partnership tables have different & frustrating effects when set in the context of organizing according to a mechanistic, command & control mindset.

Social innovation

From earliest days of schools in church basements, parents & their allies have taken responsibility for inventing most of the forms of community service that have been taken up by the system.

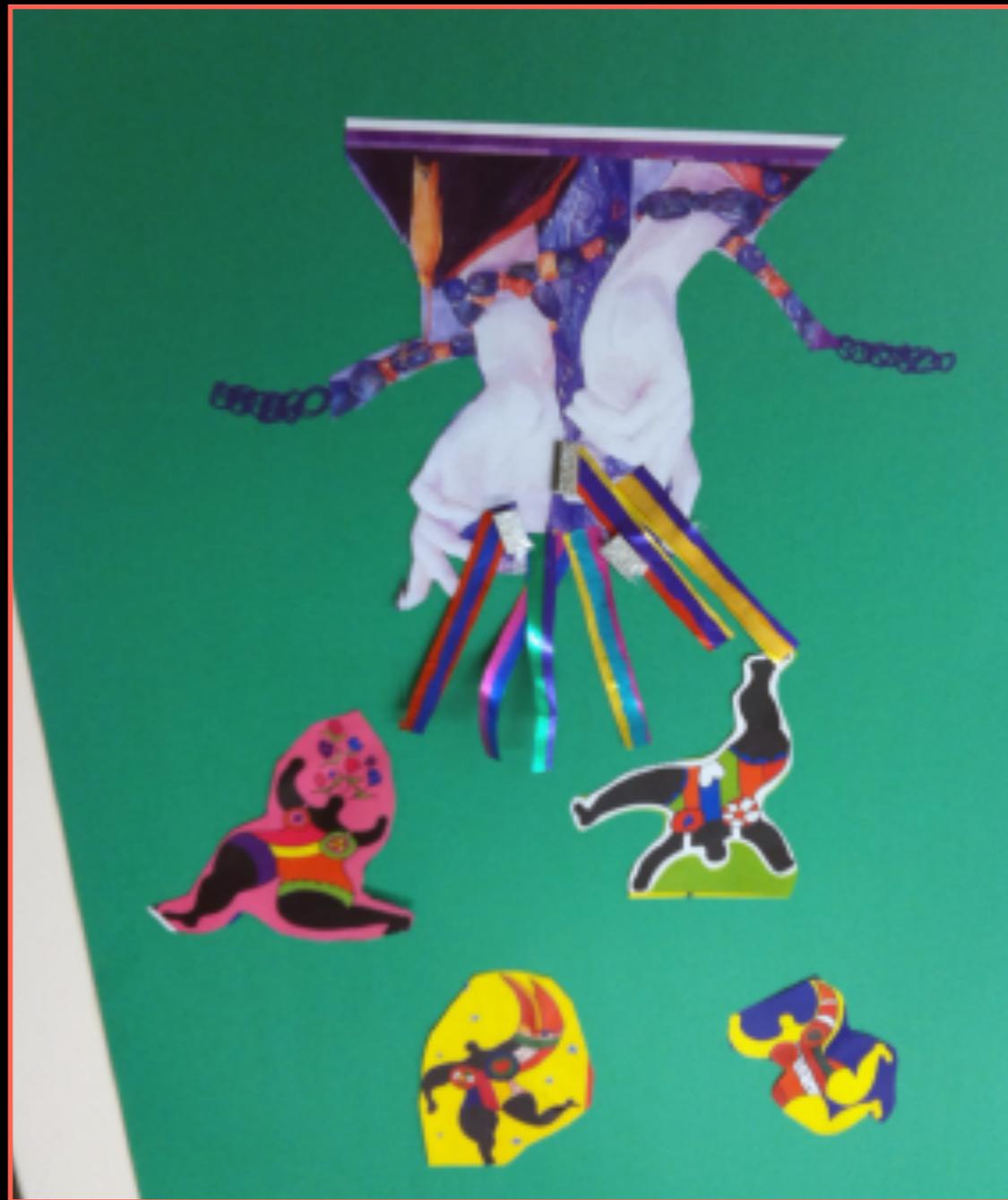
Political influence

Developmental disability services have been privileged in public expenditure in relation to other socially devalued groups.

Everyday support

58% of US adults with developmental disabilities live with family members, mostly parents.

These two collages represent the reflections of a veteran, successful parent advocate on her career and its effects on her daughter's life. She has been fearless in acting as an initiator of an early, landmark class action lawsuit, active as a member of the panel judicially authorized to monitor the system's implementation of the vindication of the rights established by the court. She has been an involved & outspoken advocate for her daughter throughout.



She notes that for much of her daughter's life, her actions were shaped by these assumptions.

Parents try a variety of gymnastic moves to entice or coerce the system's hands to deliver the colorful ribbons of resources for a good life. However the hands, bound in red tape and chained to current constraints, can't let go and give parents what they want.

Her engagement with a small agency committed to individualized supports led her into a series of learning experiences that convinced her to mobilize her networks to go for deeper change in her daughter's circumstances.



Parents shift their energy into a circle with those who know and care about one another's wellbeing. Together, they find ways to discover, attract, and organize the resources that they need for a good life. The service system is only one source of what's needed.

Creating a person-centered plan focused effort on a fundamental question that had gone unasked for more than 20 years. Forming and mobilizing around this question began with calling into question the idea that her obvious, nearly continuous un-settlement and apparent discomfort was an unalterable symptom of the combination of her diagnoses.

How might my daughter show up as a person comfortably at home?

There are common understandings of person-directed planning that seem to assume that it is a process through which a person or parent delivers answers to the question, "What are your goals?" This understanding doesn't reach as deep as a search for the most important currently unanswerable question that will encourage people to discover better & better answers by trying new things together.

Having the support of a well connected circle to hold this over time as an open question—“How might my daughter show up as a person comfortably at home?”—revealed a blind spot. Though she had done all sorts of things to try to fix the place her daughter slept, including bringing the full weight of legal and administrative authority to bear, no one from outside would be able to imagine the setting as anybody’s home. Large numbers of behaviorally challenged people, impersonal staff relationships oriented to maintaining compliance with procedures & “individual support plans”, continual cacophony...

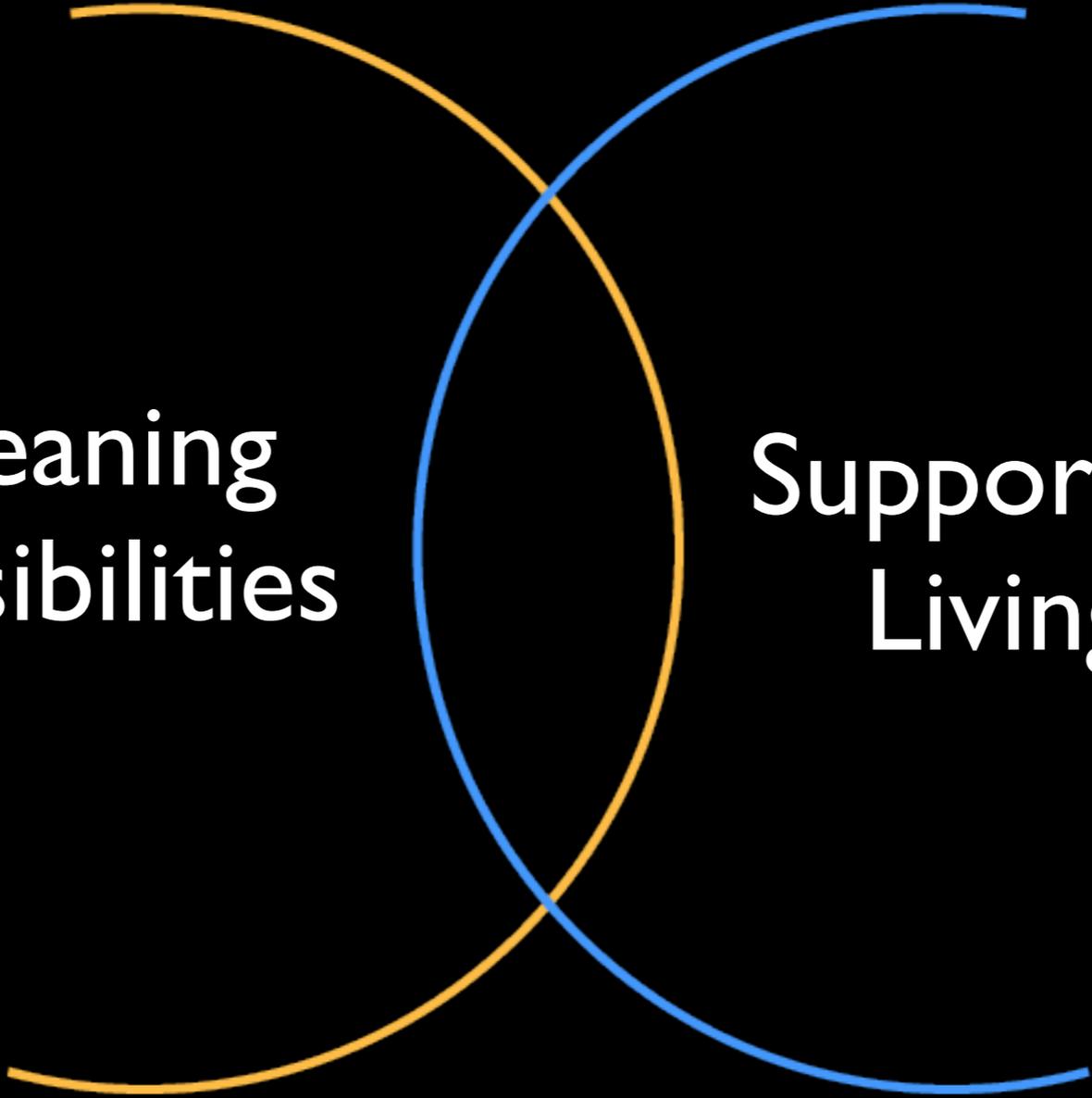
Seeing into this blind spot revealed the obvious: effort to fix the residence was making the situation worse. A new tailor-made living arrangement was necessary: there has to be a home in which she can be comfortable.

The system they rely on does not make it easy for a person who requires substantial assistance to walk out of group living and walk on to one’s own place. It took time & effort but it happened.



Supported Living

“How might my daughter show up as a person comfortably at home?” is a question that lasts. Being in her own home provided more of the conditions for living comfortably there, but much more became possible with the intervention of a gifted clinician, Martha Leary, who was able to attune people to the resource that her musical capacities can be: help with movement, transitions, getting through doorways, accessing a meditative state. This has grown in another direction as music becomes a theme for the household: going out to concerts and jazz clubs; hosting musical evenings, offering her nieces and nephews and their friends practice space.



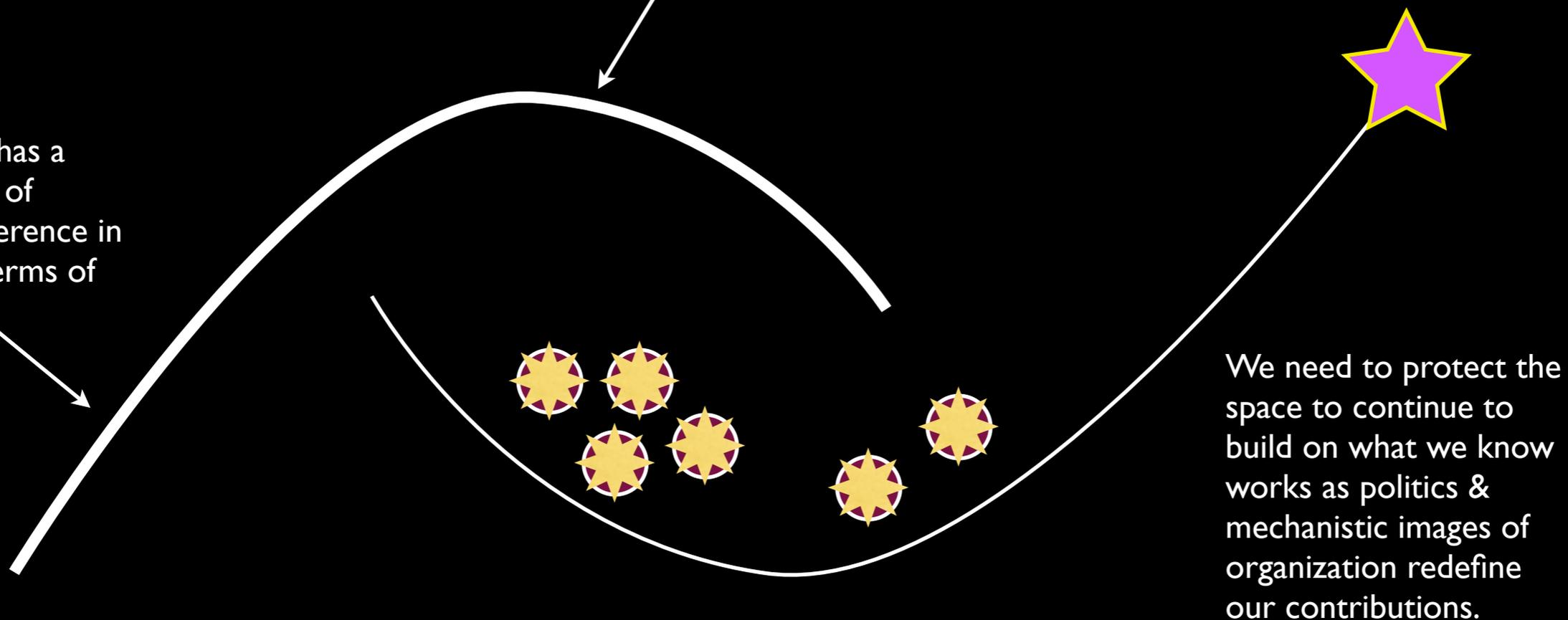
**Gleaning
Possibilities**

**Supported
Living**

It's time to walk out and walk on when the chances of good things coming from our effort in a particular system start to decline.

We've hit the limit of our ability to influence. We may maintain contact but don't invest too much energy and hope. It's time for most of us to walk on to another effort.

Our active engagement has a good chance of making a difference in setting the terms of the agenda



Community

WHAT IS IT
that makes
someone
walk out on
this idea
that they
space up.

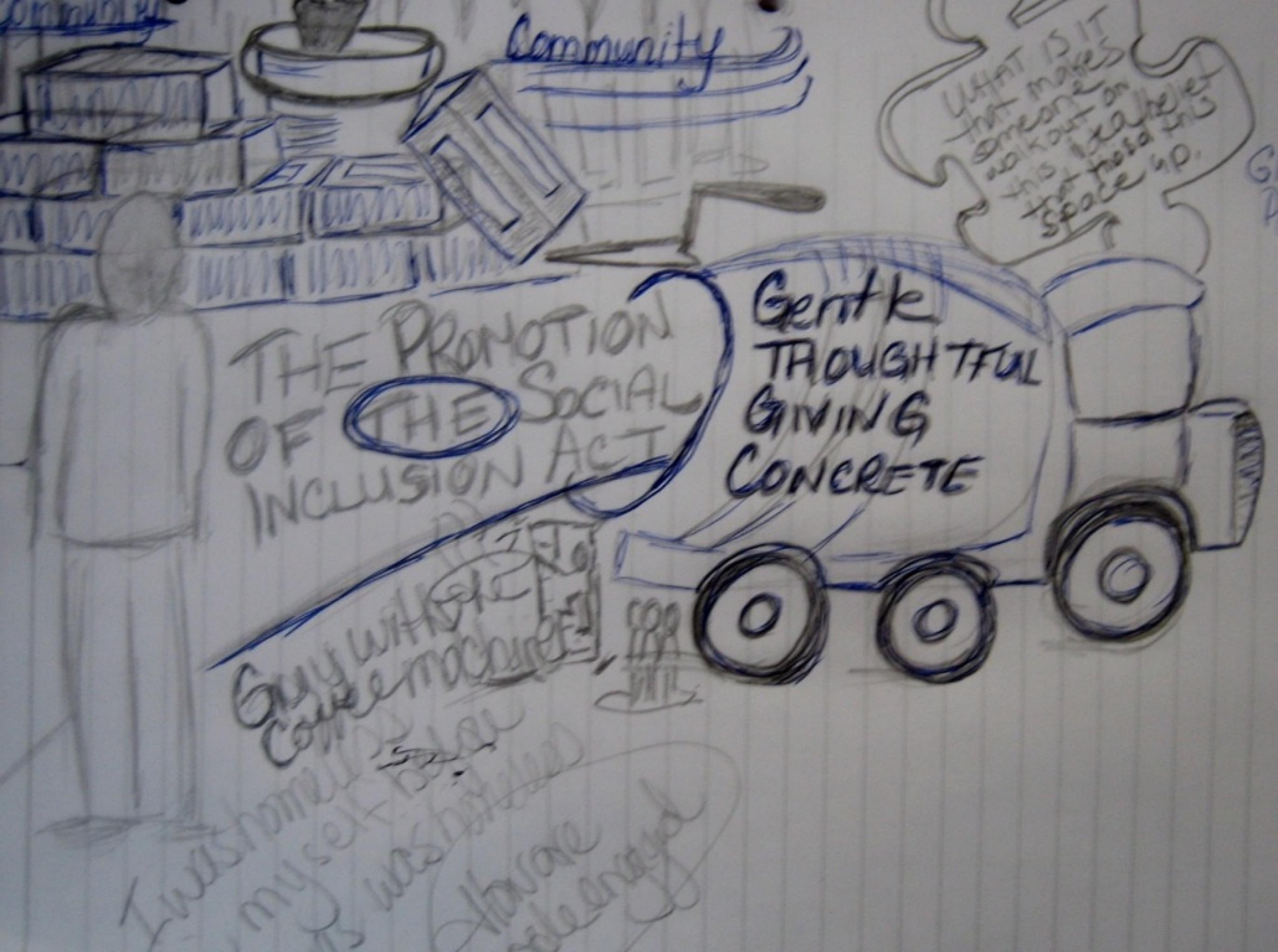
THE PROMOTION
OF THE SOCIAL
INCLUSION ACT

Gentle
THOUGHTFUL
GIVING
CONCRETE

Guy with the
course macro

COO
TAY
VILL

I was home
myself
was
I have
re-energized



Community

WHAT IS IT
that makes
someone
walk out on
this to believe
that these things
space up.

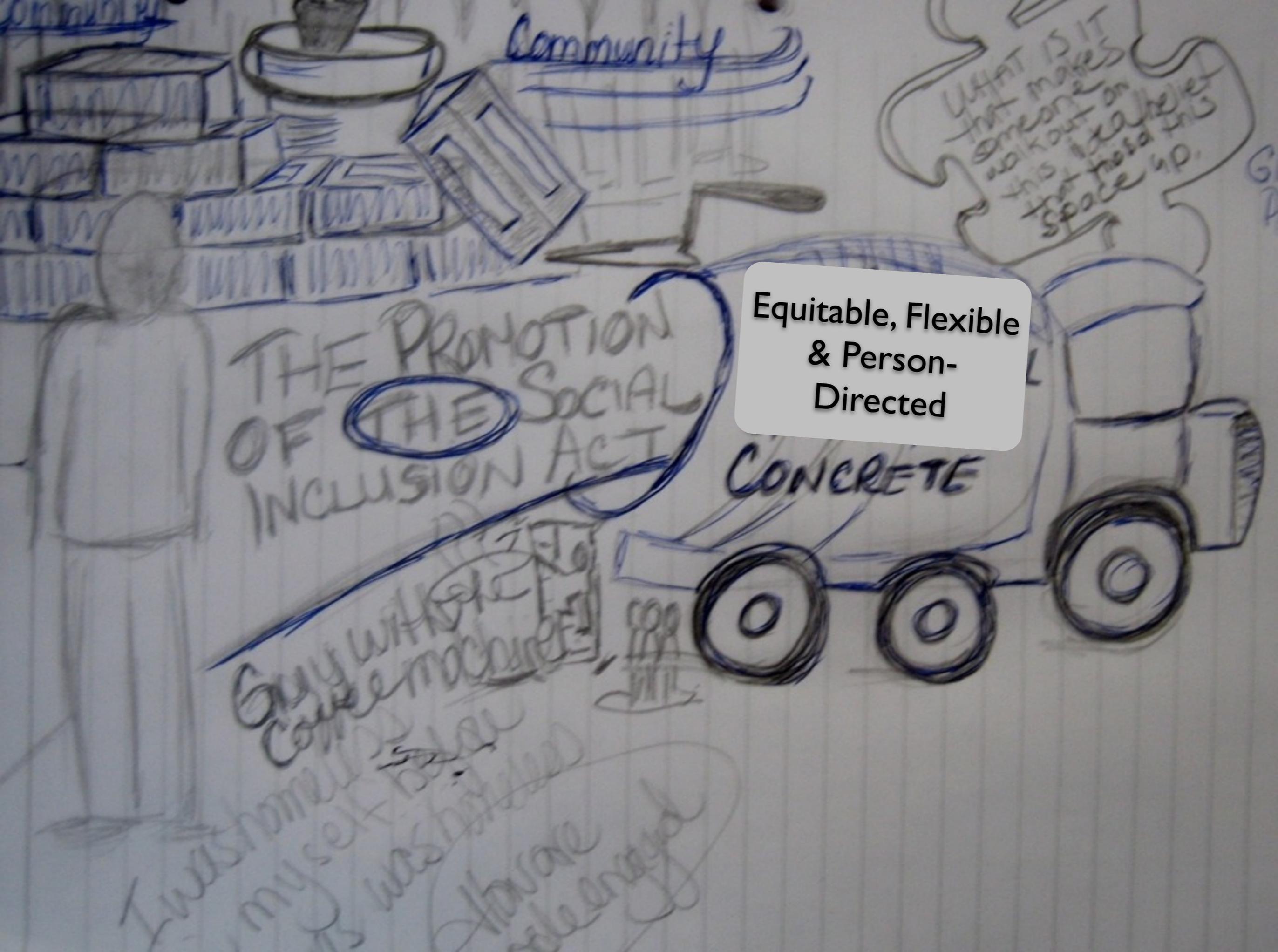
THE PROMOTION
OF THE SOCIAL
INCLUSION ACT

Equitable, Flexible
& Person-
Directed

CONCRETE

Gay with the
course macro

I was home
myself
was
I have
re-energized



Maybe we are responsible for our rhythm?

Smaller we — Bigger we

Inside boundaries — Crossing boundaries

Withdraw from system — Engage System

Rest — Work

Social innovation

Social inclusion can't emerge unless people invent the ways, at small scale and bigger scale, to open valued social roles to people and assist them to be successful in them. While much as been learned, much must be invented in each situation; it's not a technology.

Join people at risk of invisibility because
of substantial disability
at the edge of possibility
to create the social innovations
necessary for our communities to
benefit from their contributions.

Social innovation

Social innovations build new social ties that generate the practical knowledge necessary to support people to show up where they have been invisible

A mechanistic mindset assumes that social inclusion can be produced by the application of techniques. Without a deep appreciation of **source** it's impossible to organize to support the emergence of social inclusion. We need to appreciate the source of social innovation in order to walk away from practices and structures that are dead at the roots because they have no regard for **source**.

What is the **source** of the vision
& practical knowledge necessary
to encourage & guide action that
supports good lives?

One view of **source**

Larry's life changed dramatically when he was reunited with his sister, who took responsibility for advocacy, has shared her home with him, & supported his career as an artist. Proper assistive technology, facilitated communication,* has opened many possibilities including starring in a movie.

Reactivated family ties + Committed assistants + Skilled use of professional knowledge = Better life



*Institute on Communication & Inclusion http://soe.syr.edu/centers_institutes/institute_communication_inclusion

I'm bouncing around the system as it's trying to figure me out.
I just want someone to risk it and hear what I have to say.
I am not a victim just got a real story to tell.
I can't speak but I need you to listen.
I'm more like you than not like you.
I'm more like you than you'll ever know.
I hurt like you and cry like you.
I'm more like you, wouldn't you like to know?
Not with a bang but a whisper, all the foundations fell.
As the old guards protested, I armed them with a smile.
I was there when it happened as they washed their faces clean.
It's only fair, I need to be counted.
I'm more like you than not like you.
I'm more like you than you'll ever know.
I hurt like you and cry like you.
I'm more like you, wouldn't you like to know?
Don't believe your eyes. What you see is not real.
Please do not deny. I will be revealed.
I'm more like you than not like you.
I'm more like you than you'll ever know.
I laugh like you and cry like you.
I fight so hard everyday to let you know.



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GERARDINE WURZBURG

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TRACY'S BLOG

LARRY'S BLOG

watch
the
trailer

INSTITUTE ON
COMMUNICATION
AND INCLUSION
at Syracuse University

What is the root cause of our dissatisfaction/ apprehension?



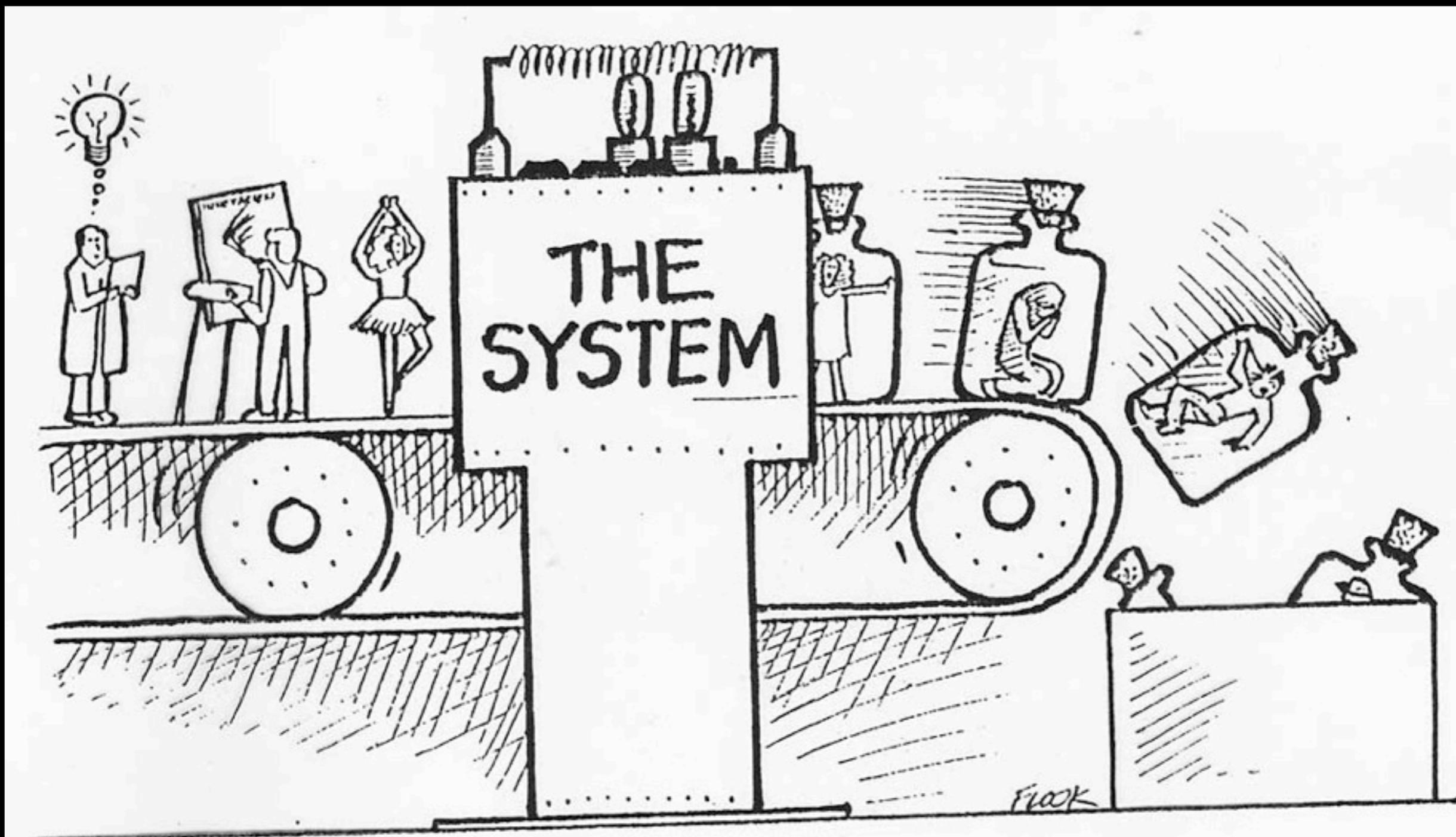
Social Inclusion

Fairness & Flexibility

Independence & Choice

Person-directed Planning

Direct Payments

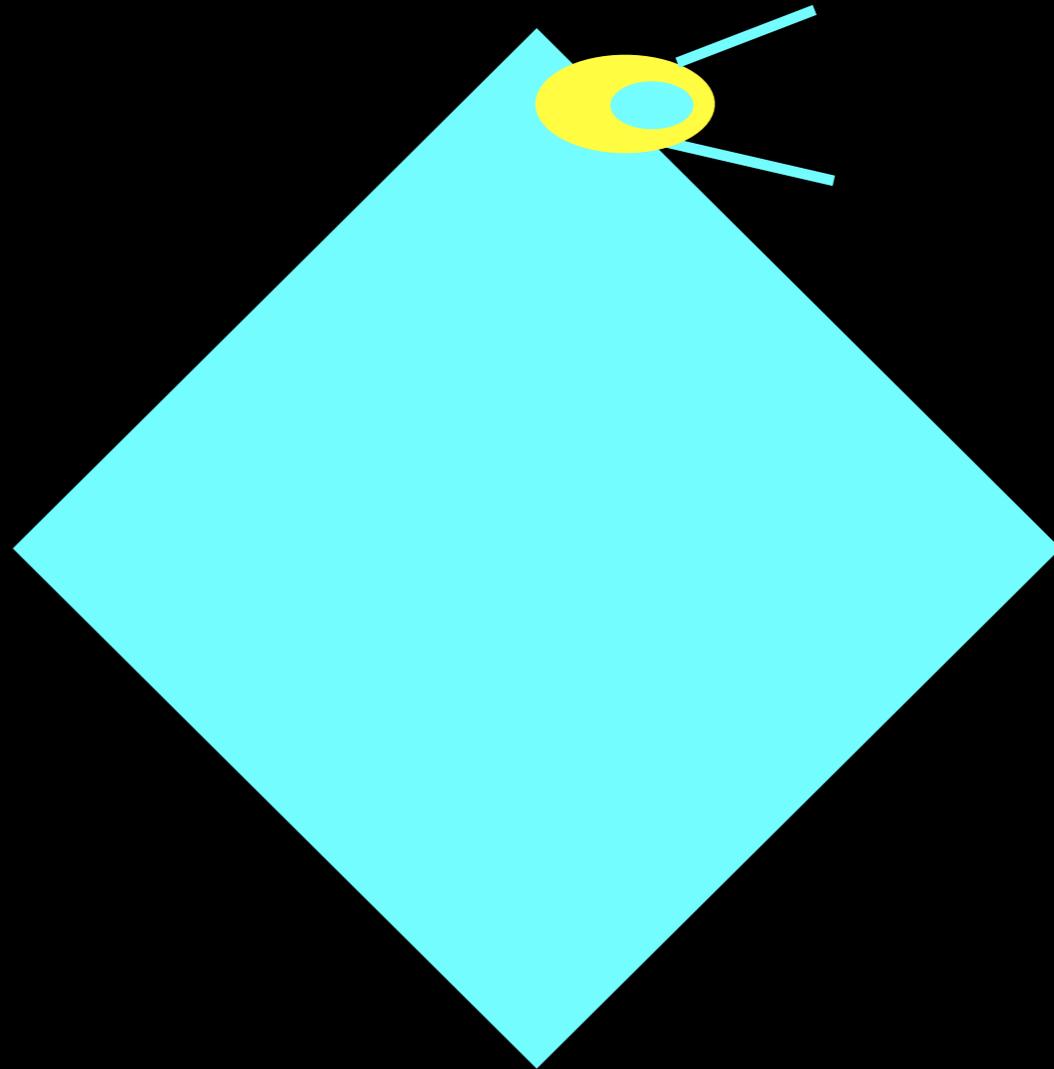


We depend in important ways on a system that acts as if it can be “transformed” by command and control. We sense the misfit with what we know is truly necessary for good lives to emerge and this unsettles us. Our efforts to influence the system lead to more of our words being taken into bureaucratic structures, but we can’t hear the music.

We need to be mindful of the power of the structures the system has created to get its necessary tasks done. We can think of these systems as different sets of eyes (“gazes” if you want a fancy disability studies term) on person and family. These different eyes have their own legitimacy and can perform useful work; they just can’t in themselves support the social inventions necessary to allow a more inclusive community to emerge.

Clinical eyes

Diagnosis
Prognosis
Prescription
Compliance



“objectivity”
distance

Administrative eyes

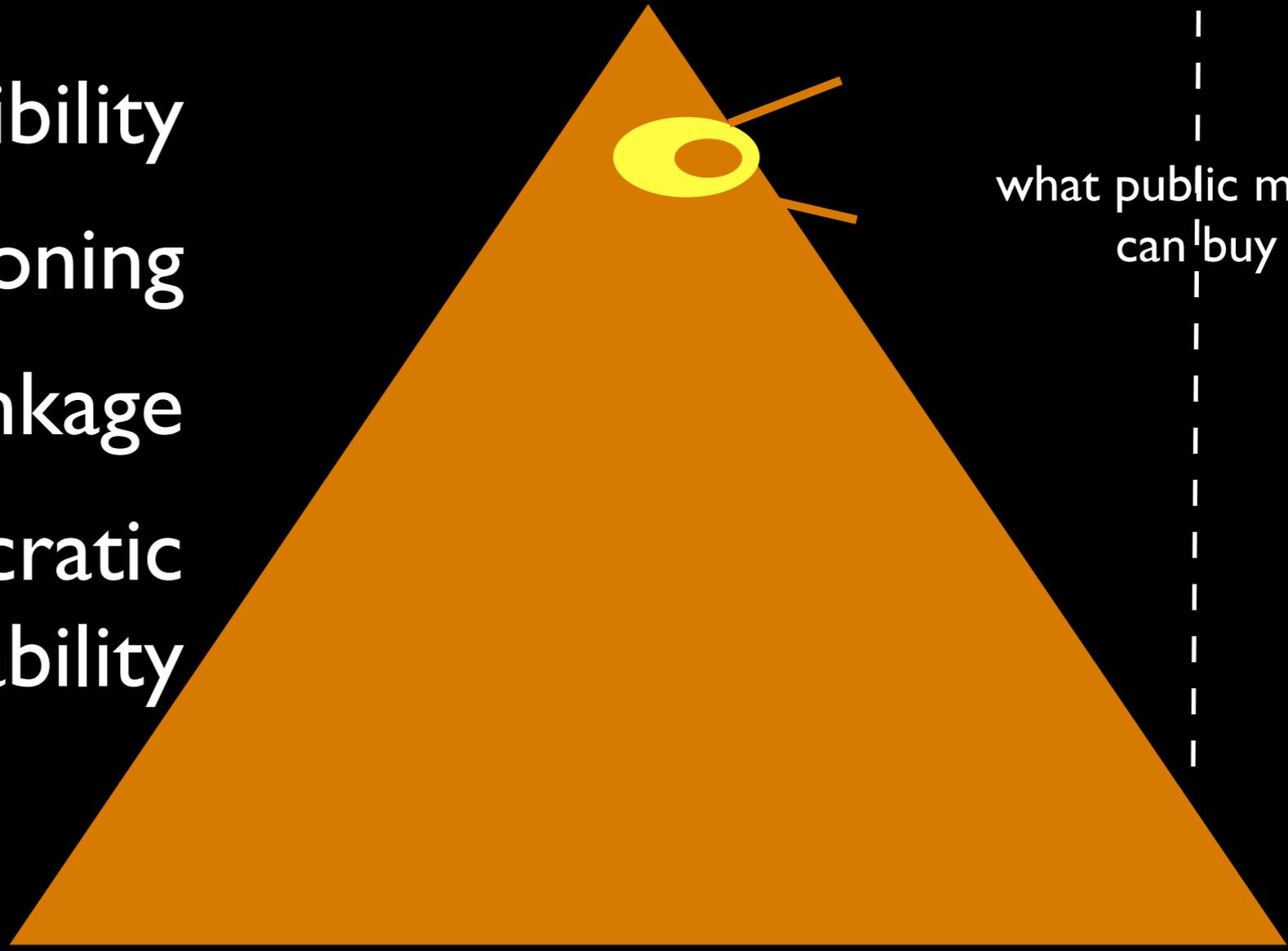
Assessment of need

Eligibility

Allocation/rationing

Interagency Linkage

Bureaucratic
accountability



what public money
can buy

“objectivity”
impersonal fairness

Service management eyes

Specification of goals &
tasks

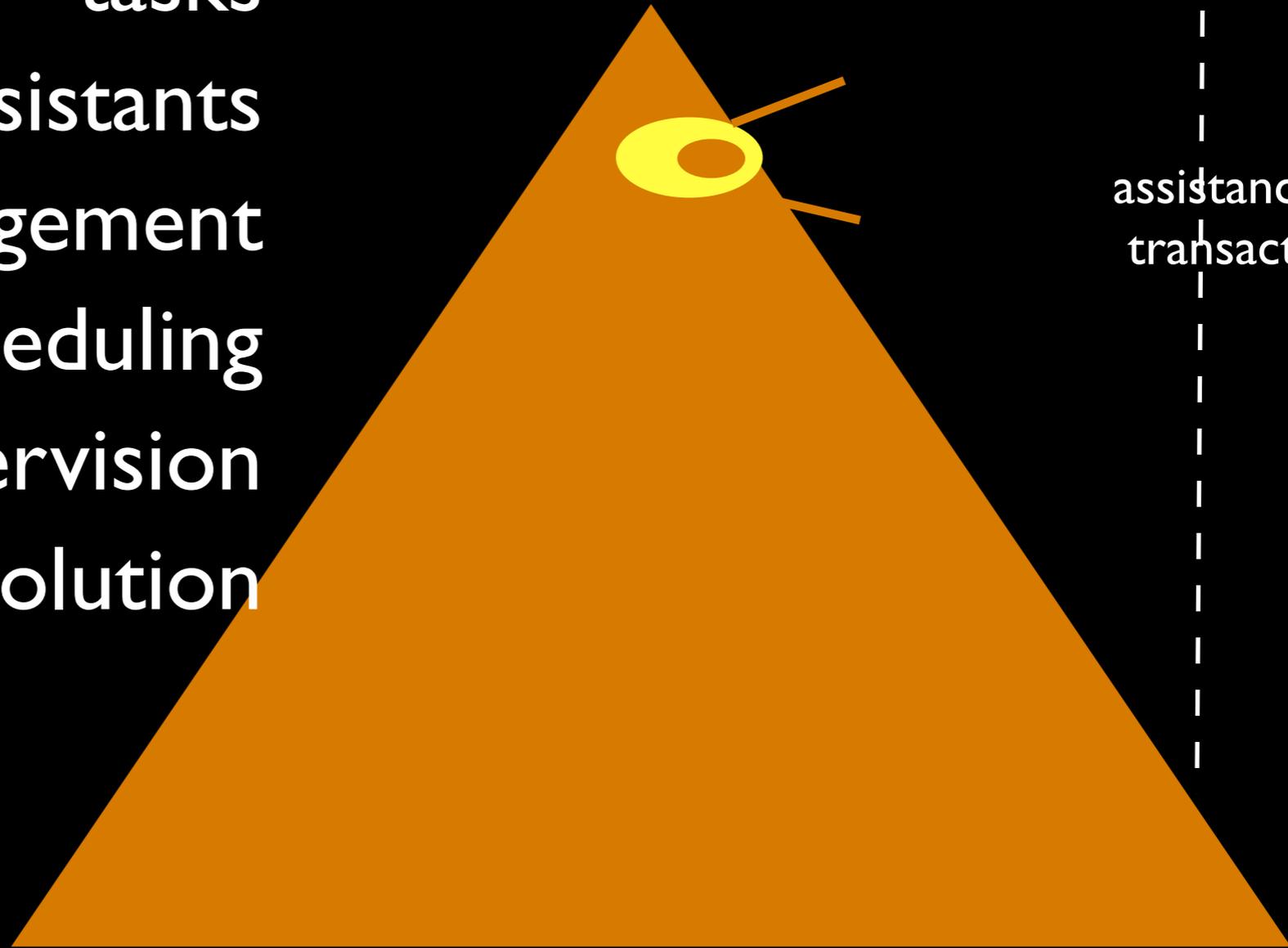
Assignment of assistants

Risk management

Scheduling

Supervision

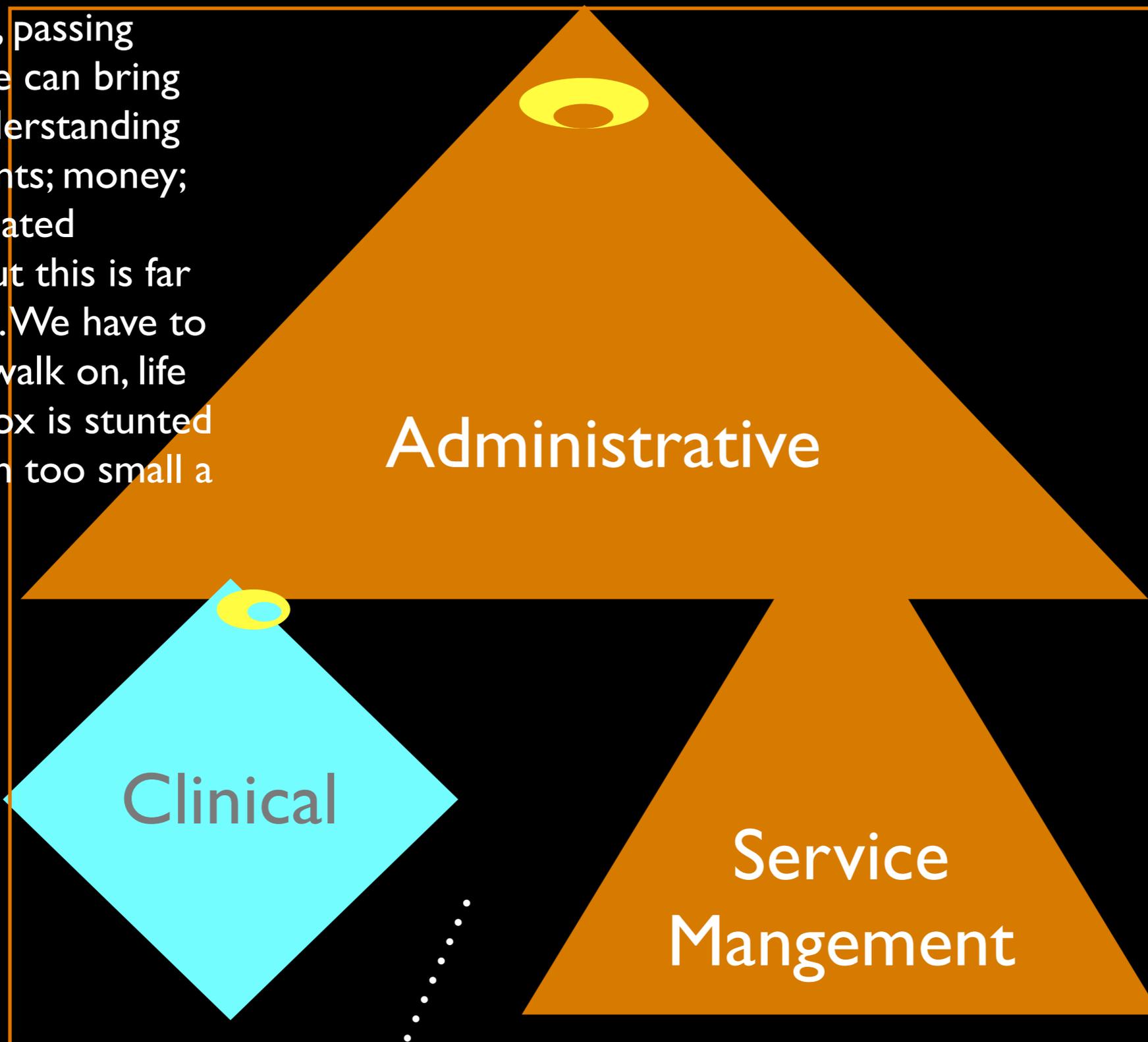
Conflict resolution



assistance as
transaction

conformity to
contracts &
standards

When these functions are effective, passing through here can bring benefits: understanding of impairments; money; well coordinated assistants. But this is far from source. We have to walk out & walk on, life inside this box is stunted like a plant in too small a pot.



Walk On



Walk Out

Eyes on a positive future

?

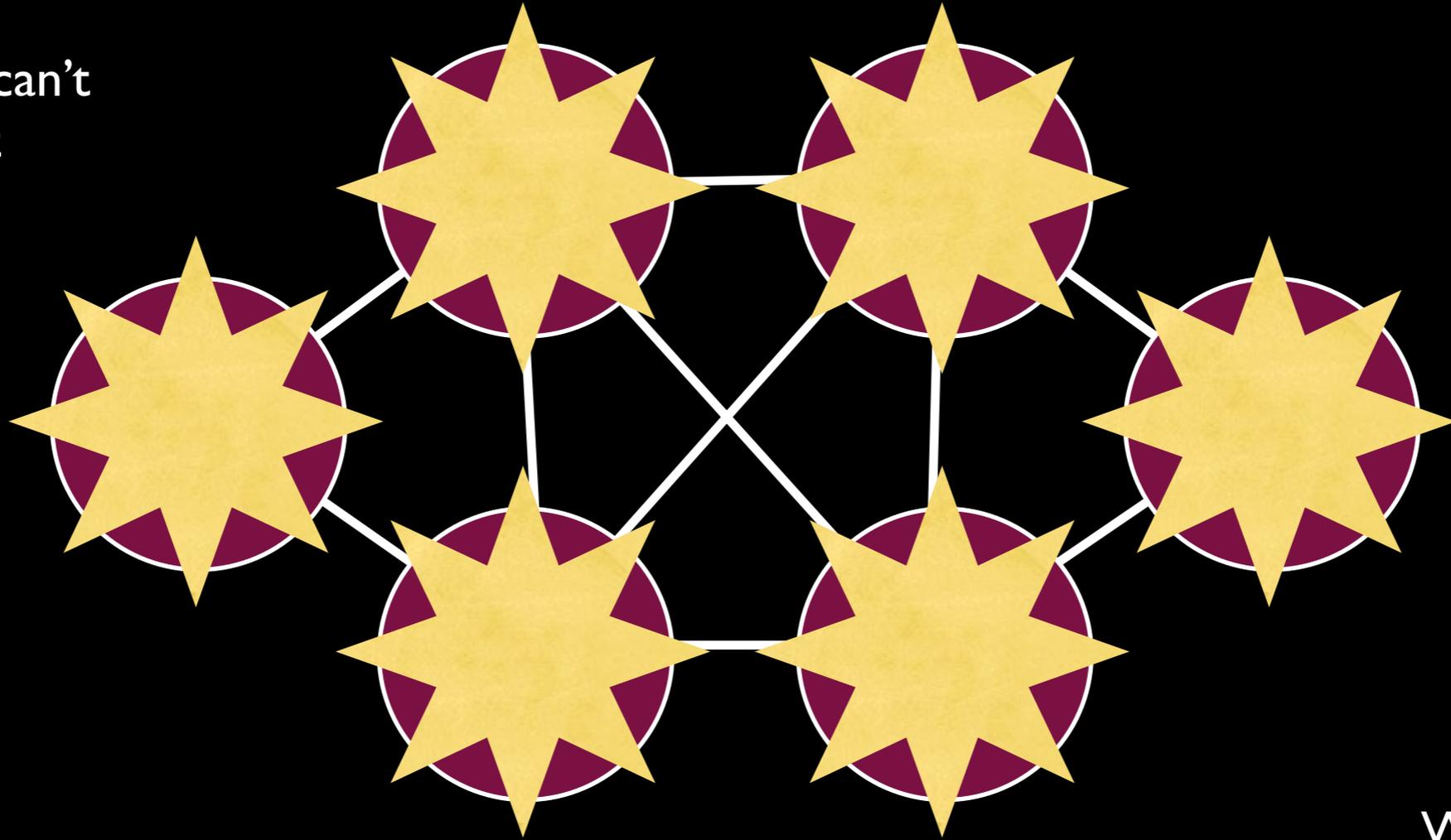
What gifts can you
bring that express your
highest purpose and
build your community?

Disciplines & practices that
invite **source**

Relationship:
personal
engagement

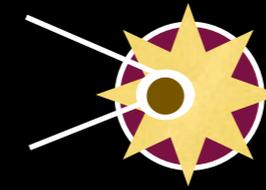
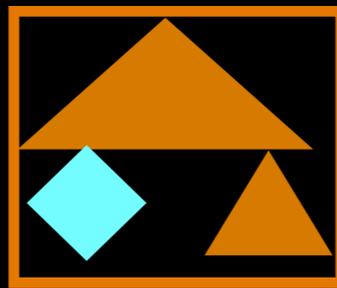
Active search
for possibility

Walking out can't
mean going it
alone.



Lots of actors trying different approaches
Some connections - exchange of stories
Willingness to try and tell

What we need is
social inclusion is
to emerge at a
community scale.
Policy test: does
this policy make it
easier for people
to do these
things?



Assumptions (maybe taken for granted as common sense) that define the box we can see once we have walked out of it.

Accountability = documented conformity to detailed specifications

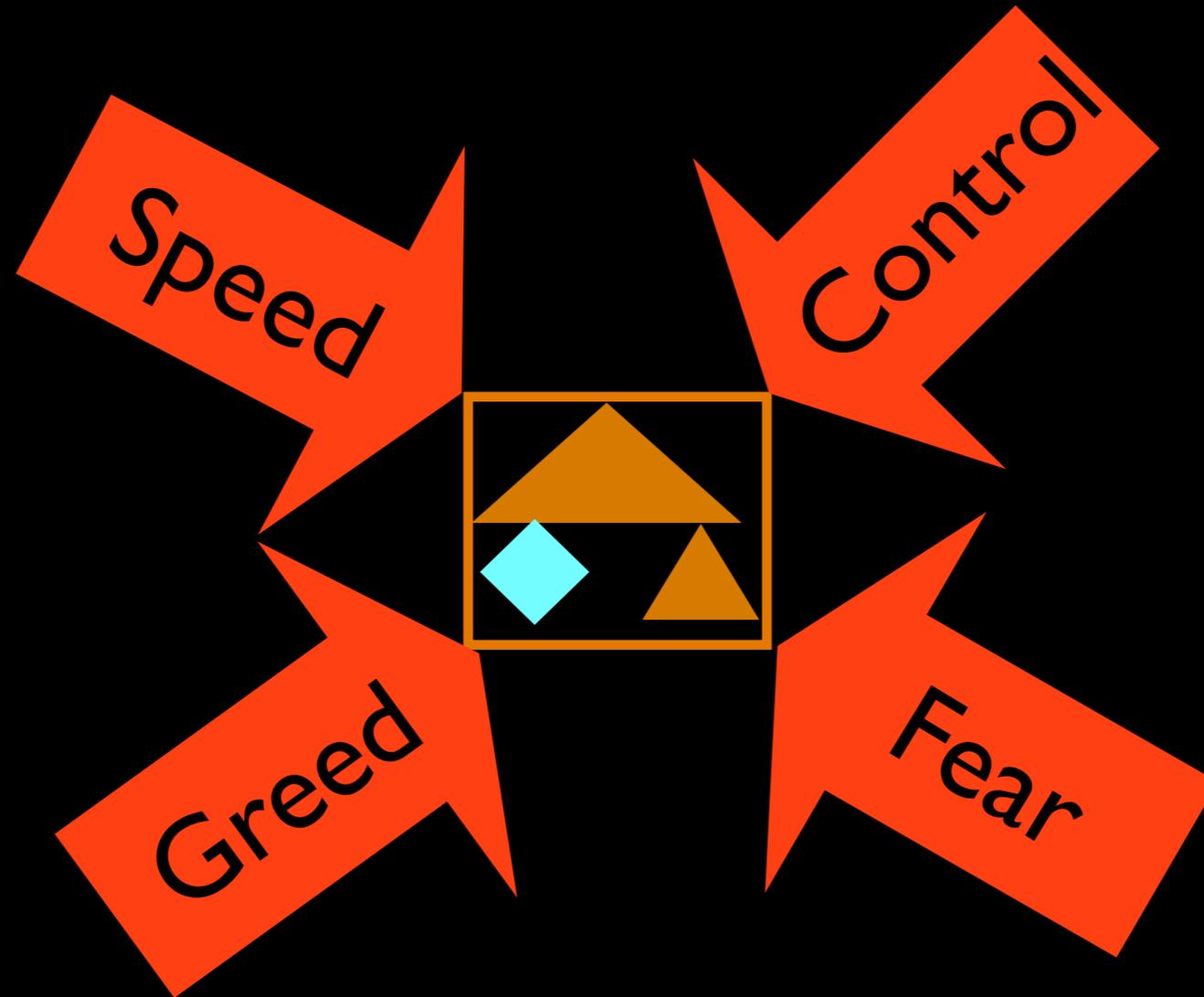
Objectively determinable need justifies uniform, cost-effective allocation = fairness

Efficiency results from the action of a market in which government controls both buyer & seller behavior

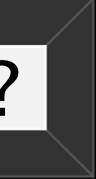
People will do what they are told, given well defined tasks, proper incentives & close monitoring

Trust is a risk to minimize

A system based on these assumptions can reliably produce person-directed supports & social inclusion



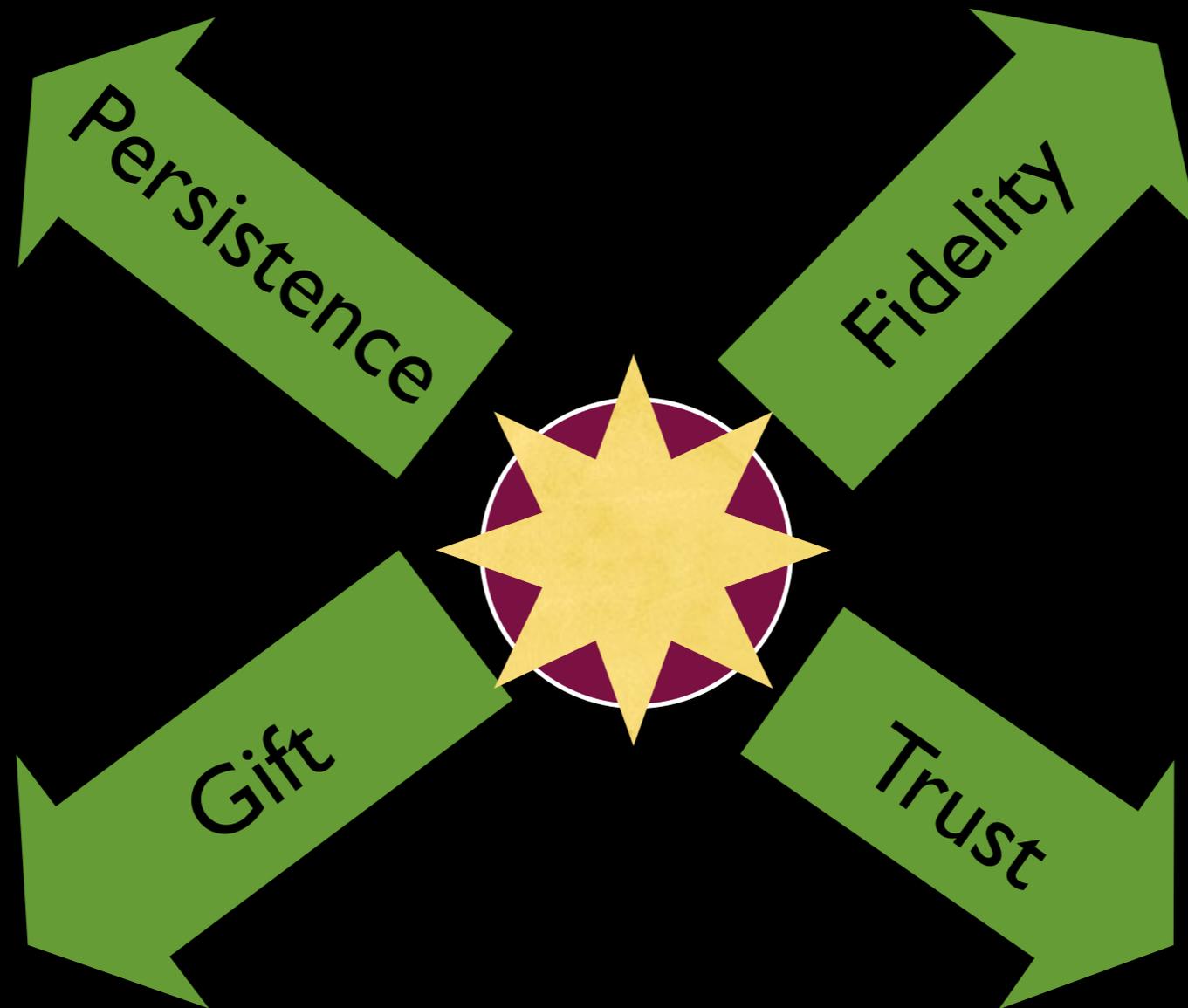
Powerful cultural forces that shape confining assumptions. We need to resist at this level, by acting outside this space, living different values and acting on different assumptions.



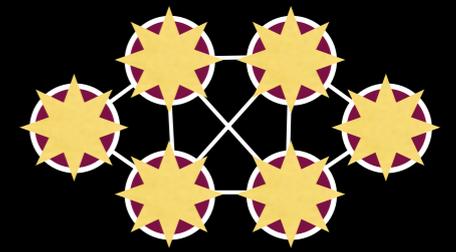
***Rise up with me against
the organization of misery***

–Pablo Neruda

One way to state the values that will express resistance as we walk out of the confines of mechanistic systems and walk on to a more just & inclusive community.



Social inclusion arises from...



...relationship building: time & shared stories

...clarity of vision that supports confidence to GITFIO in unfamiliar spaces

...intentional learning about collaboratively shaping valued social roles in a gift micro-economy

...commitment to creativity in assistance

...risking trust

...fidelity to commitments that can embrace failure & fallibility

If you want to walk
fast, walk alone.

If you want to walk
far, walk together.

– African Proverb

