What supports good lives in community?

National Federation of Voluntary Bodies Challenging Times: Ensuring Values 23 June 2011 John O'Brien
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Do more with less!



But there's more to do

Alternatives for people when its time to move out

Better support to people living with their families

A better deal for people in congregate settings

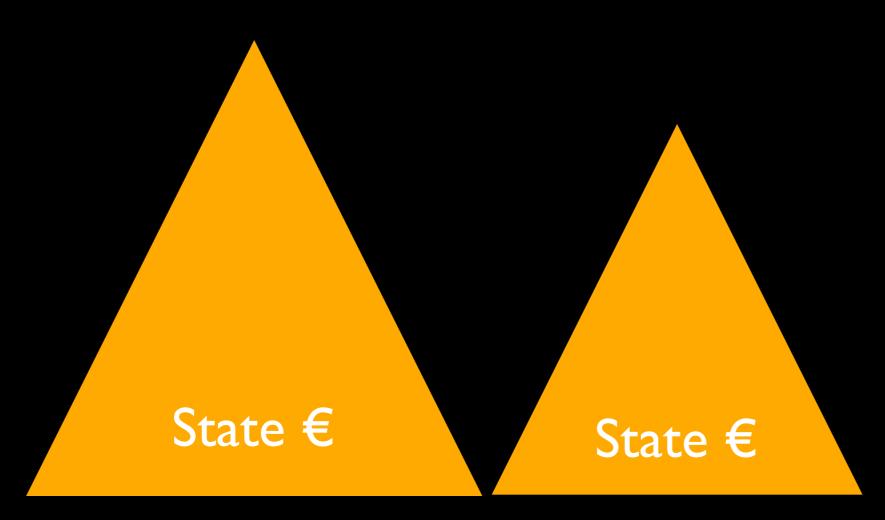
Elders with ID?

Valued community roles for all, especially people with substantial needs for assistance

Do more with more

When state funding is shrinking, where does "more" come from?





Decrease not to scale (yet)

From assuring that we are making the highest use of the € we have & from making decisions about highest use based on our resourcefulness in learning to mobilize all available capacities.

Extended families capacities

Person's capacities

Organizing

More X

Social Innovation

A systematic process

Staff capacities

Community capacities



Individualized, flexible €

Responsiveness to role expectations

Connections

Resiliency

Responsiveness to knowledge

Skills, knowledge

Willingness to offer support Capacity

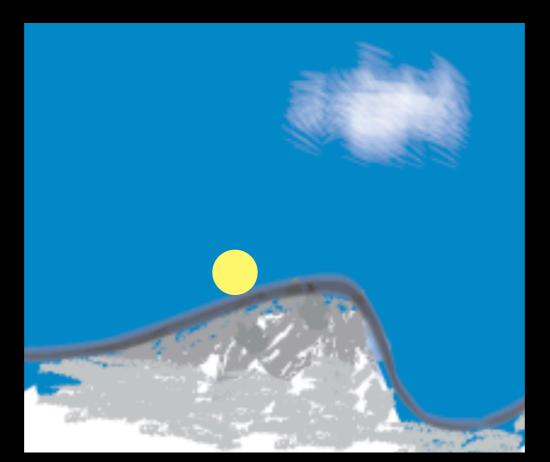
Time

Willingness to learn through action

€

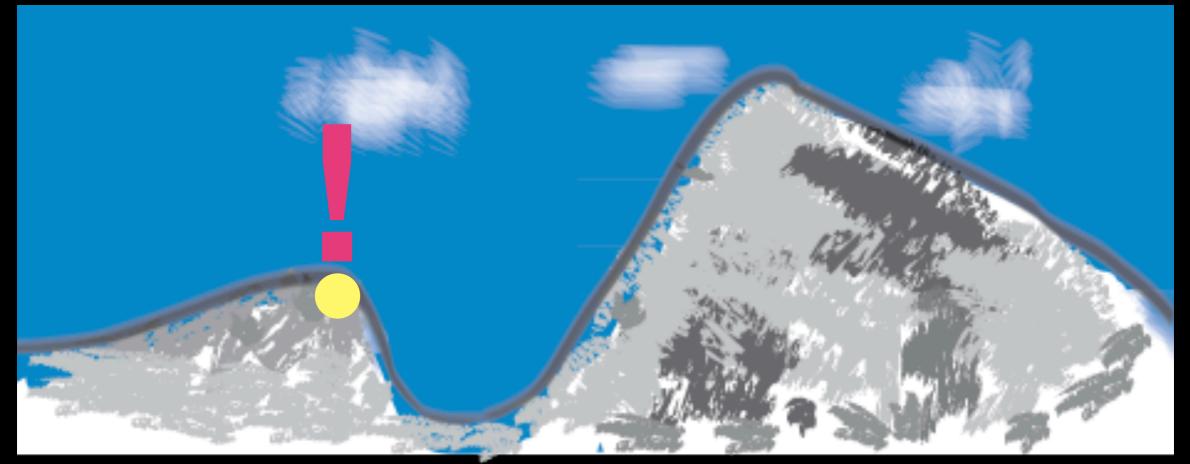
Desire for better

For a generation, we have learned to be successful at climbing this mountain: accepting sole responsibility for the consequences of complex processes of social exclusion & bringing increasing numbers of people with disabilities into an increasing variety of need defined programs.



Climbing Mount Program

As a field, we have mastered this core process to the point that it has become reflex. E.g. increasing numbers of elders with ID tempts us to identify a new need & wrap that need in new programs, which often call for new real estate & newly specialized staff. Repeating this process many times builds skills + political muscle around program development & management.



As we summit of "Mt. Program", we may also be passing the high point of public per person investment in people with ID, raising a question about the sustainability of our current pattern of wrapping need in programs.

More important, from the summit of this first mountain, through the lens of the UN Convention, we can see another mountain to climb, a mountain whose slopes engage us in the deep change necessary to actively assist people with ID toward full social inclusion + genuine self-direction. Frighteningly, the path to the second mountain leads down into the state of uncertainty necessary to the learning we need to do to move on. We need to come down from reflexive power-over people with ID and their families & find ways to practice power-with and open the social roles & self-determination that allow people to act as contributing citizens. We need to re-negotiate our settlement with families, schools, work places, & community associations to move from accepting delegation to keep people safe, healthy, and happy at the margins of society to assisting the re-negotiation of social boundaries necessary to open access to valued social roles.

We create value by supplying & supporting

trustworthy

Re-centering our efforts calls for re-considering the core of our work. This understanding emphasizes that it is right relationship that liberates citizenship.

respectful

resourceful

people

who are willing

to be recruited into relationship by the person to participate in imagining better to act with the person & allies to support contribution in community life



We also need to re-consider our ways of thinking about how our work gets done.

Program thinking can make us mindless & lead to under or overservice.

The next page –from O'Brien & Callahan (2010) Employment support as knowledge creation. Research & Practice for Persons with Severe Disabilities 25, 1-2, 31-38— is an example of a way to think about employment that draws on the experience of implementing Customized Employment with people who are typically failed by usual approaches in Supported Employment. Thinking this through led us to a support matrix that encourages mindfulness about capacities at every step of the process of assisting employment.

To learn more about customized employment, visit www.marcgold.com/Publications/index.html

Actions by/with Job Seekers	Natural Support + Reasonable Accommodation & Technology	Support to Ordinary Processes	Negotiation of Personalized Conditions & Contributions
Decide to work	Job seeker makes his/her own decision to work with-out assistance/support.	Job seeker gets encourage- ment and support from family and allies to consider employment	Job seeker and allies are enrolled in customized employment and assured work will reflect the person.
Identify focus: job or interests, conditions and contributions	Job seeker reflects on local job market and personal interests and considers good match.	Job seeker receives typical assessment for employment and is assisted to identify job match.	Job seeker receives facili- tated discovery to assist in identifying conditions, inter- ests and contributions.
Get the job	Job seeker uses personal connections and those of allies to make employer contacts.	Job seeker is assisted by a job developer to find open jobs that match interests.	Job seeker is represented by a job developer to negotiate a custom fit with personal conditions, interests and contributions in relation to employer needs/benefits.
Succeed on the job	New employee receives supports as typically offered to all workers, including reasonable accommodation.	New employee and employer receive support by a job coach to perform the job responsibilities of the position filled.	New employee and employer receive support from a job coach to perform the duties of the customized job description.

Go only as far to the right as necessary

← Move to the left as soon as possible

The path from programmatically "meeting the growing needs of the aging person with ID" to "the cat-whisperer at work" shows the opportunities for drawing on capacities that come with assuming uniform, high-intensity need across functions,



	Ordinary processes + accommodation + technology	Specialist assist ordinary processes	Negotiate contribution & conditions			
Decide to work			X			
Identify capacities			X			
Get the job		X				
Succeed	X					

Some young people with significant impairments have the personal, family, & employer capacities to succeed on the job with no employment service resources needed.



	Ordinary processes + accommodation + technology	Specialist assist ordinary processes	Negotiate contribution & conditions
Decide to work	X	Assumed	
Identify capacities	X	Assumed	
Get the job	X	Assumed	
Succeed	X	Assumed	



Tracy

My family is my greatest place of stability but my idea of independence is having my own home to hang my hat, to set up in the way I choose. Mom has been there my entire life to help me on my path to being the independent thinker I want to be.

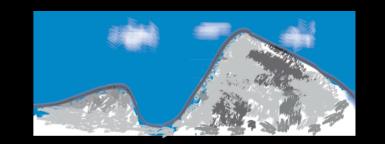
It is my time to search for the place I want to live that is both independent oriented but gives me the right thinking type of support I need. By that I mean it is necessary for me to have physical cues to get my body moving not bossy final answers made by others. My dream is to be in my own place where I make choices of the groceries I wish to buy; the decorative theme is of my choosing; the communication is open; the weekends' activities fill my desire for exercise.

The most important thing is the commitment to learning how to support my typing. I have to let it be known that my family would never turn me from their home; this is my desire in my search for being in control of my life that I want to make for myself. I know my fans mean well to help in my residential search. For me it is more than a hook to hang my hat on; it is being in peace in my way of living where I make the house rules in cooperation with my like minded roommate.

From Tracy's blog, which you can follow at www.wretchesandjabberers.org, an example of the sort of demand we need the flexibility to meet; group living and typical supported living don't work for Tracy & everyone will be better off when we can respond to each person without needing to have a programatic slot in inventory. Tracy also reminds us that people can outgrow even good & loving situations in which they live with their families.



More when...



People have better life chances when these things are true. They offer a measure of effectiveness. For example, we could test the effectiveness of special education + family supports by determining how many young people arrive at their 18th birthday able to say that these five things are true for them.

Experience of a variety of community roles that provide knowledge of interests & capacities

Confidence based on experience that they can take action, solve problems, & deal with breakdowns, difficulties, & prejudiced treatment

A hopeful & positive vision for a contributing community future.

A diverse network built on reciprocity + willingness to ask

A practical understanding of impairment