

Let's talk about caregiver behaviors that become barriers to progress for citizens with disabilities

STOP IT!

SPECIAL EDITION
For Direct Care Professionals

presented by

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3 things...

× OVER-PROTECTION



× OVER-SUPPORT



× UNDER-PREPARATION



What drives us?

**Presumed
Incompetence**
– they are
here because
they can't, I
am here
because I can

**DUTY
OF
CARE**



SURVIVAL/exhaustion
– just getting through
every hour of every day is
tough.

**JOB
SECURITY**

**The Medical
Model of
Care**

**Cultural
Differences**

**Lack of guidance,
training & encouragement**

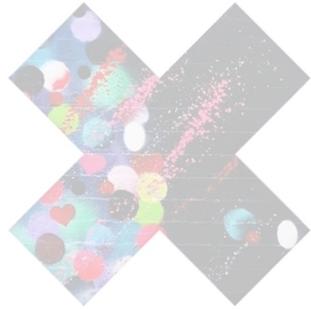
**Workplace
barriers**

What are some of the results?

BEHAVIORS DRIVE

EVERYTHING – when there are no demands, then others place demands, the shock & resistance to the new demands cause the person to be labeled a “behavior problem”

**DEPRESSION
HOARDING
EVICTION**



REDUCED SELF ESTEEM

– they believe they can't when we always do everything for them

**Increased danger of
ABUSE & NEGLECT**

RELATIONSHIPS

between family & systems caregivers are difficult, can cause breakdowns in communication or even dismissal.

LACK OF PREPAREDNESS for the real world, or for the next environments in adulthood, mean far more limits to housing & living options, more churn by caregivers, inconsistency and anxiety

**Lack of a sense of
home, increasing
isolation and
loneliness**



“

**Lowered expectations
may take the form of sympathy,
kindness, or generosity,
but they can be quite harmful to the individual
by limiting the amount of constructive feedback
that is received.**

**This negative feedback keeps the individual in an
inferior and dependent position.**

Smart, J. (2016). Disability, Society, and the Individual. United States: PRO-ED, Incorporated.

”





This treatment can shape a person's attitude towards his/her disability and limit what they are willing to do, regardless of what they are able to do.

Karen Y Sanders, "Overprotection and lowered expectations of persons with disabilities: The unforeseen Consequences" April 2006, IOS Press.

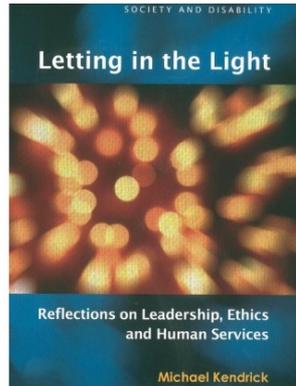




Why you are important

Dr Michael Kendrick

Speaker, consultant and author in values based leadership, service design and reflective practice in the community services sector for over 30 years.



It is not always obvious to us that our personal efforts in our communities make all that much difference on any given day. Nevertheless when we step back and view it over a longer period of time there are often signs that give encouragement. This is the case with what may seem the rather 'ordinary' efforts of everyday service workers in helping people with disabilities to be more fully a part of their communities and to fully enjoy it. The very simplicity of these contributions often masks their potential profundity and importance. That is why it is important to give them the recognition they deserve.



Your role right now



**SHIFTING
HOW WE
THINK**

The (GUIDING) Principle of Normalization



The principle of normalization in
human services WOLF WOLFENBERGER



NATIONAL INSTITUTE ON MENTAL RETARDATION

Source: Wolfensberger, Wolf P.; Nirje, Bengt; Olshansky, Simon; Perske, Robert; and Roos, Philip. "The Principle of Normalization In Human Services" (1972). *Books: Wolfensberger Collection*. 1. https://digitalcommons.unmc.edu/wolf_books/1

- "The **normalization principle** means making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society."

The (GUIDING) Principle of Normalization



WWIW?

WWID?

ALWAYS ASK YOURSELF:

What would I want?
What would I do?

“Othering” ourselves to better understand the impact



The principle of normalization in
human services WOLF WOLFENBERGER



NATIONAL INSTITUTE ON MENTAL RETARDATION

People who work in support jobs are called “Direct Care Workers” and yet, you are so much more. You are parents, daughters and sons, artists, singers, gamers, athletes... when we use just one word to describe you, you become one-dimensional and the perception is that you only have value in one area: as a care worker. The rest of who you are is unknown, ignored, not considered important. Family members whose loved ones are in supported care situations often fail to use the principle idea when they think about the direct care professionals as people who can have a bad day, be struggling with serious challenges at home, and so they may not always be at the top of their game each and every day.

Yet our differences are important to realize

The realities of living the life of a person with disabilities

- Presumed incompetence everywhere they go
- “Last in the room”
- Conditioned/learned set of action/responses that are rote and inflexible
- Taught to always say yes and agree
- Living in a rock concert on a fast moving train
- People (staff, therapists, etc) have been coming in and disappearing without explanation most of their lives; has an impact on relationships and trust
- 4 times more likely to have experienced abuse by age 18. ⁽¹⁾



Let's talk about **CHANGING** caregiver behaviors that become
barriers to progress

STRATEGIES

The (GUIDING) Principle of Normalization



The principle of normalization in
human services WOLF WOLFENBERGER



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Source: Wolfensberger, Wolf P.; Nirje, Bengt; Olshansky, Simon; Perske, Robert; and Roos, Philip. "The Principle of Normalization In Human Services" (1972). *Books: Wolfensberger Collection*. 1. https://digitalcommons.unmc.edu/wolf_books/1

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Approaching with intention

Making plans to support in new ways at home and in the community

Survey Says...

STRATEGIES

ORGANIZATION LEADERS AND CAREGIVERS list of most helpful skills upon arrival:

1. Flexibility
2. Willingness to try new things
3. Personal Care & Environmental Responsibility (cleaning, care of spaces, tidiness)
4. Functional Communication
 asking for help, reporting problems, indicating pain
5. Interpersonal Communication/Social Skills
6. Problem-solving skills

ADDITIONAL RESPONSES include: self-advocacy, safety in public, meal prep, taking meds, following a schedule.

Create the learning tools

- **Make a list of the things that are expected in the setting**
Examples: personal care, showering, dressing/undressing, getting up, getting to bed, laundry, housekeeping, asking for help, teamwork, taking turns, asking for help
- **For each specific task, work with a clinician to break the task down into steps (activity schedules).**
- **Create these task lists on paper using visuals and simple language if necessary.**
- **Post these task lists or make them available to staff at all times.**
- **Train the direct care professionals on how to read, follow and teach the steps.**

Create a Plan

What we do for Sara right now	Can Sara learn to do it (or part of it) herself?	What is needed for Sara to get to her highest level of independence?	Who is needed to help Sara learn?
Take her to a store while we shop for groceries	She could push the cart/find items on shelves/unload at checkout/pay	Pictures of the items to look for, training on how to move a cart around, following a list, using a credit card at checkout	staff at the house to prepare, 1 or 2 staff at the store, behaviorist, transportation/driver
Setting the table for a meal	She could get the dishes, bring them to the table & set the table with verbal prompts, or she could put the cups on the table, announce that dinner is ready to peers	Make sure she can reach everything and knows where everything is; she needs the language to use with peers ("it's time to eat!"); verbal prompts paired with visuals then fade verbal prompts	Staff at home who can provide the prompting as needed until faded, behaviorist
Stand next to her during a group activity to participate	She could participate for a shorter time to start, with less prompting	Staff need to stand further away, maybe use a timer to build time up, reduce expectations of compliance & allow her to participate in her way, practice skill alone first	Clinical plan to fade prompts and build skills, trained staff

Progress, always!

Current View	Stage 1	Stage 2	Stage 3
Going to the park in the van	Going to an event at the park	Volunteering for setup or breakdown at event	Volunteering regularly & becoming relied on
Buying something at a store	Regular visits to a LOCALLY owned store	Going with a list	Volunteering to stock, going with others, helping peers find items
Setting the table for a meal	Putting placemat, dishes & silverware at each place	Getting everything out of the cupboards, setting up the table	Announcing that dinner is ready to each peer, asking peers to help, loading dishwasher
Having lunch with peers	Bringing in a favorite object/picture to share	Inviting others to bring in favorite objects; take pictures & make an album	Ask families to host lunch once a month or quarter on a weekend

The Sabotage Game

TEST – DON'T GUESS

Link to the Sabotage Game Document (all rights reserved)
<https://bit.ly/SabotageGame>



A shift in thinking that helped build a friendship

THE STORY OF ANDY

<https://youtu.be/zpK6KKzuFzY>



A shift in thinking that helped build a friendship

Quote from Andy's ACTUAL caregiver:

“It wasn’t my job to BE his friend. It was my job to support him in his own journey to finding friends.”



A shift in thinking that helped build a friendship

- HELP people meet people*
don't protect them from it
resist the urge to explain
- The learning curve is OURS, not theirs
- Be consistent
- (PS - think about ways this can also be applied at home between housemates or with visitors)



* The contribution of human service workers in getting the relationship "right" between people with disabilities and their community
CRUcial Times 21. Community Resource Unit Ltd. Brisbane, Queensland, Australia
July 2001



Supporting progress **as a support team**

- One-page profiles for ALL⁽¹⁾
- Communication logs with special section for skills work/progress
- Solution Circles exercise ⁽²⁾
- Time & space for conversation: developing authentic support relationships to build trust
- Awards ceremonies to announce & celebrate & recognize progress

(1) <https://onepageprofiles.wordpress.com/>

(2) <https://bit.ly/3WbwX0j>



LET'S REVIEW



Why you are important

The Flipside

ALL OF THIS takes time and effort and intention, BUT

**Putting in the commitment, time
& work means**

A well-prepared young adult with all sorts of options for living & working

FEWER HEALTH ISSUES



More chance of STABILITY, which fosters even more progress

CONFIDENCE & SELF-ESTEEM

Building blocks for positive, healthy, happy, meaningful **RELATIONSHIPS WITH OTHERS**

A person who is ready to learn, grow, face challenges and improve their own quality of life.

HAPPINESS

The knowledge that you are making a difference in lives!



Part of a winning team



for you

Renewed sense of purpose in your life

STRENGTH



Greater sense of pride in your work!

Better relationships with those you support, that give you the freedom to enjoy time with them & improve your work environment



Expanded future employment opportunities





In our everyday efforts in our communities, it is important for us to remember that it is always the few that precede the many, the small that beget the large, and the obscure that humble the famous. It is important that service workers not become persuaded that their efforts do not matter, as we would all be the poorer for their absence.

CHERYL

Ryan Chan



You cannot hope to build a better world without improving the individuals. To that end, each of us must work for our own improvement, and at the same time share a general responsibility for all humanity,

our particular duty being to aid those to whom we think we can be most useful. ~ Marie Curie

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THANK YOU

very much!

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