

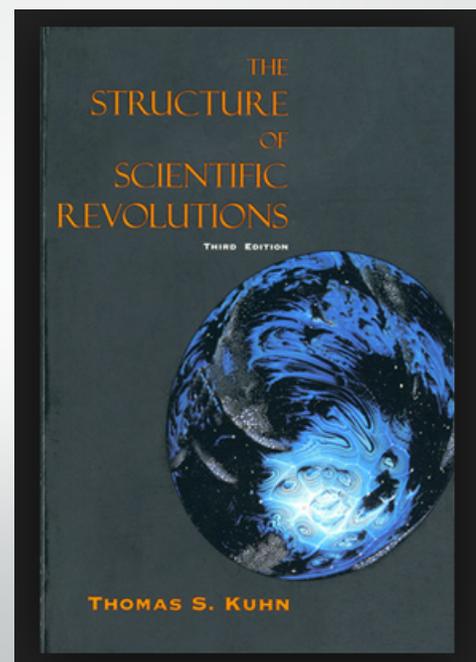
The Supports Paradigm: Why understanding people with disabilities by their support needs changes everything

James R. Thompson, PhD.

Reykjavik, Iceland

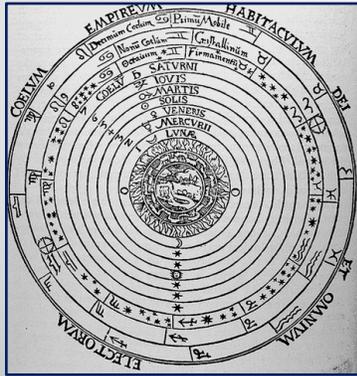
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Premise: Advances in any scientific field proceed via **paradigmatic shifts**. When errors and contradictions emerging from the application of a paradigm become untenable, the search begins for a better paradigm that provides more satisfactory solutions.

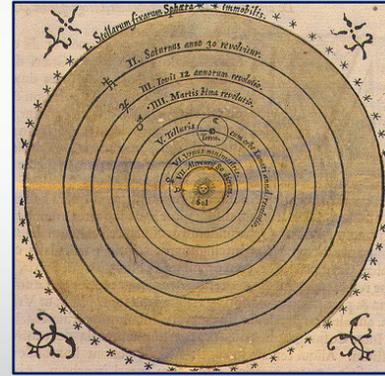


Paradigmatic Shift: An example

Ptolemaic Astronomy



Heliocentric Astronomy



Joshua 10:13 - And the **sun stood still**, and the **moon stayed**, until the people had avenged themselves upon their enemies. Is not this written in the book of Jasher? So the **sun stood still** in the midst of heaven, and hastened **not to go down** about a whole day.

Paradigms in an applied field

... the *widely accepted truths, assumptions, and viewpoints that guide people's work*

Describe the paradigm associated with the applied field of human services to people with developmental disabilities.



Prior Paradigms in services to people with developmental disabilities

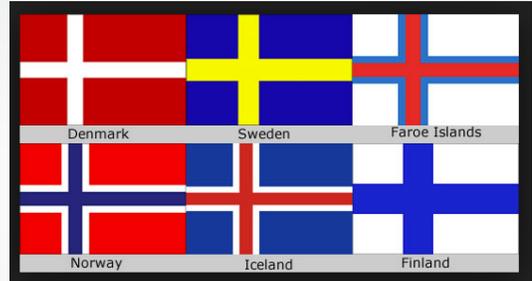
- The Medical-Institutional Paradigm
 - disability is a deficit within the individual, a condition that prevents functioning or participation in activities (Pledger, 2003)
 - the goal of professional services should be to remove the pathology (i.e., fix or cure the person) in settings where expertise can be gathered and treatment and care can be most efficiently delivered
 - the interests of people disabilities can be addressed by consolidating services in hospital type settings and sending people to these settings to receive remediation services

The Medical-Institutional Paradigm

- Had some successes
 - Disability caused by PKU has been eradicated in much of the world
 - Prenatal Vitamins (Folic acid) significantly reduces the risk of a mother giving birth to a child with spina bifida
 - The debilitating effects of alcohol on a developing fetus are well known
- Remains relevant to the work of professionals in the field who are involved in prevention and medical treatment – but that is a relatively small number
- Had tragic shortcomings
 - Being understood as a person lacking a desirable trait (i.e., human intelligence) resulted in people being marginalized and devalued by the larger society
 - Institutions became “hospitals”; people had to earn their way out of the institution by demonstrating improved competencies – most never did, and spent their lives in segregated settings where few others in society would choose to live

The Normalization-Community Services Paradigm

- Enter Bengt Nirje and the Nordic Countries!
- “The normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (Nirje, 1969, p. 181).



Some very good questions:

- Why wouldn't people with disabilities want the same types of life conditions and experiences that are valued by the vast majority of others from the general population?
- Wouldn't it make sense that denying people access to culturally valued settings and experiences harms their learning and development, and therefore exacerbates their limitations and problems?
- Why are people wasting their lives away in institutions, when they could be contributing members of society?

To which the old Medical-Institutional Paradigm did not provide good answers

The Normalization-Community Services Paradigm

Deinstitutionalization (moving people out of and preventing new admission into institutions) - achieved through developing **Community-Based Services**

Nirje's (1969) Normalization Guidelines

Normalization means a normal rhythm of the day (e.g., getting out of bed and getting dressed in the morning; eating meals and snacks as the day proceeded; having things to do, people to see, and places to go)

Normalization means living in a world with both sexes (e.g., opportunities to date, marry, and engage in intimate and loving relationships)

Perske's (2004) Reflections on Institutional Life

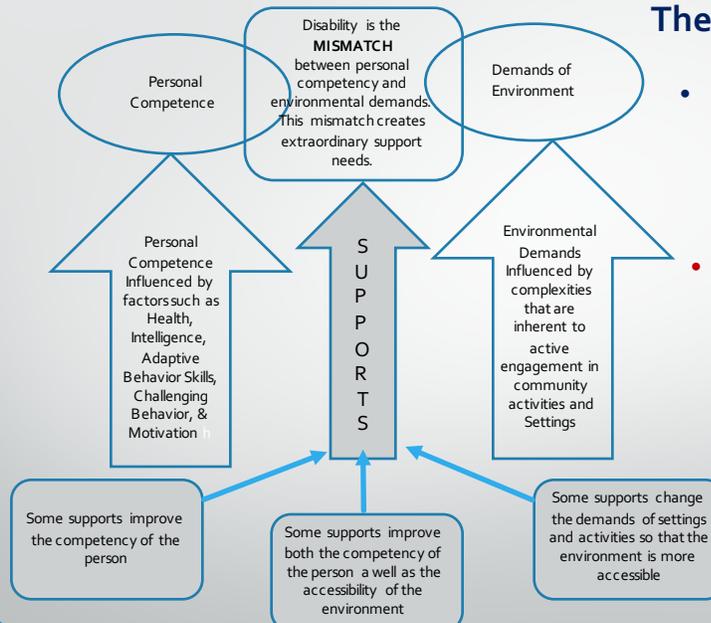
"The rhythm of the day at the institution where I worked was remarkably abnormal. All of our residents were dressed and fed before the 7 a.m. shift change. They were in bed by 8:30 in the evening."

"Periodically, the recreation department scheduled a Saturday night dance, but many staff members were pressed into action, too - watching the residents like hawks."

The Normalization-Community Services Paradigm

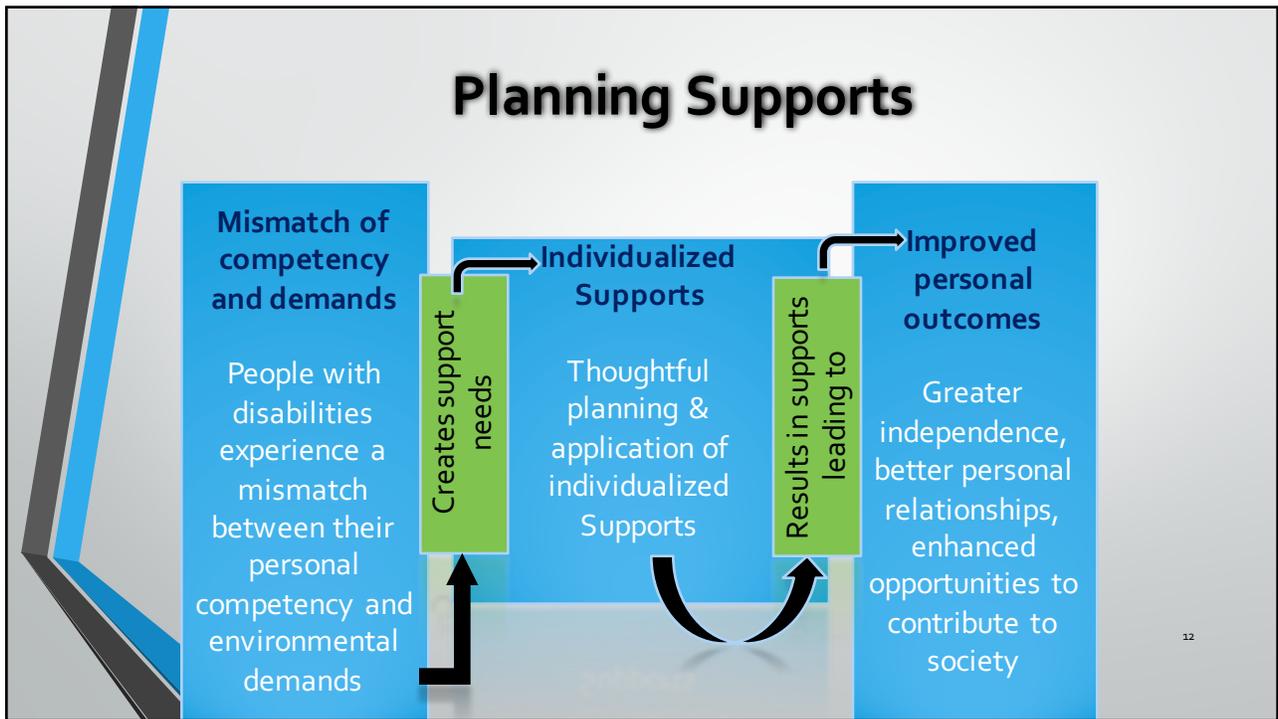
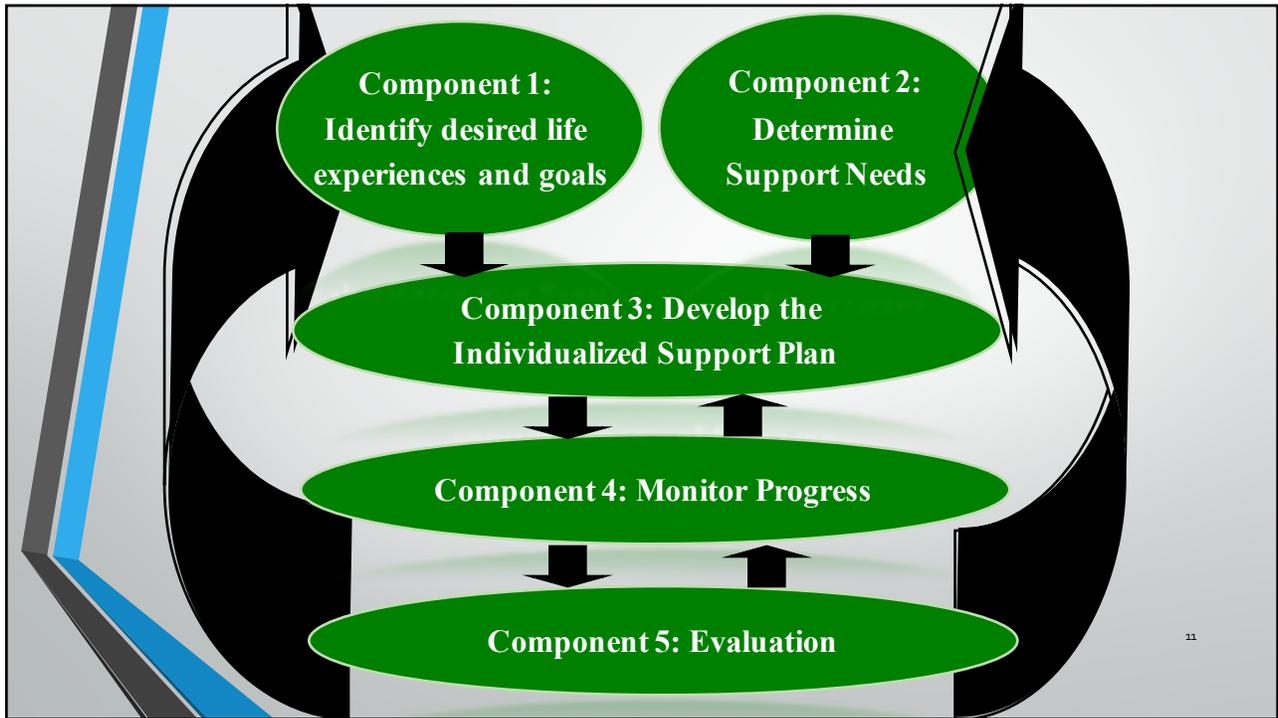
- Had tremendous successes
 - Institutional populations have been reduced throughout the world
 - People living in community homes on their own or with just a few (5 or less) housemates has dramatically increased; There are community vocational and recreational services in most communities
 - Overwhelming evidence that people who moved from institutions to community benefited
- But, shortcomings were noted – **the paradigm needed to change!**
 - Provider organizations exert much control over people's lives - people don't have choices other than what the provider organization is offering; it is a "system centered" world of community services
 - Many people with disabilities feel socially isolated within their communities; they are physically included but not socially included
 - People continued to be understood by their deficits - deficits limit opportunities

The Supports Paradigm



- Is based on a social-ecological understanding of disability

- A social-ecological understanding of disability is different than a medical understanding



Meet Beth



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Description of the Supports Paradigm

- Person-Centered – the needs and aspirations of the person with the disability and their family members direct the provision of human services and development of personalized supports
- Focus is on understanding people by their support needs, and identifying, arranging, and delivering supports
- Supports are anything that enhances opportunities for success in settings and activities in which the person is engaged

Description of the Supports Paradigm

- Supports function to bridge the person-environment gap
 - Assure basic needs are met – food, safety, shelter
 - Promote inclusion, participation, empowerment & meaningfulness
 - Activate the seabed of dormant possible selves
- Finding and arranging supports drives the work of the planning team & professional efforts
 - requires problem solving & prioritizing
 - Is a never-ending quest, not a destination

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