

AT SERVICE DELIVERY: ***Living in the State of Stuck!***

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ICDR webinar: Accessible and Assistive Technology,
Telecommunications, the Web and Disability Issues

First ever *World Report on Disability* by WHO and the World Bank:

Charts the steps that are required to improve participation and inclusion of people with disabilities [focusing on] concrete actions at all levels and across all sectors... to promote social and economic development and the achievement of the human rights of persons with disabilities across the world.

Shares goals with the UN's *Convention on the Rights of Persons with Disabilities* and the *Americans with Disabilities Act*.

World Health Organization. (2011). *World report on disability*. Geneva, Switzerland: author. Available from:
http://www.who.int/disabilities/world_report/2011/en/index.html

These efforts share many goals:

To enable persons with disabilities to attain and maintain

- ▶ maximum independence,
- ▶ full physical, mental, social and vocational ability, and
- ▶ full inclusion and participation in all aspects of life.

**AT is fundamental to the
achievement of these goals!**



Let's Look at a Few Examples

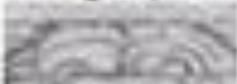
Difficulties that May be Experienced by Individuals with Cognitive Disabilities and Examples of Relevant Support from Everyday and Specialized Technologies

ICF Mental functions – Specific	Examples of Behavioral Observations	Examples of What May be Difficult	ISO 9999 class	Technologies (Low to High-Tech) (Note, many fit into multiple categories)
<p>Psychomotor (b147)</p>  <p>Specific mental functions of control over both motor and psychological events at the body level</p>	<p>Agitation and restlessness, poor eye and hand coordination, slow speech, frequent and/or inappropriate gestures such as hand-wringing</p>	<p>Participating in social situations and conversations</p>	<p>05 18.21 Assistive products for training in sensory integration</p>	<p>SNOEZELEN Multi-Sensory Environment [http://www.snoezeleninfo.com]; one-switch and free computer games [http://www.oneswitch.org.uk]; other computer games appropriate for persons with cognitive disabilities [www.nanogames.com]</p>

Scherer, M.J. (2012).

Assistive Technologies and Other Supports for People with Brain

Impairment. New York: Springer Publishing. ISBN-13: 9780826106452

ICF Mental functions – Specific	Examples of Behavioral Observations	Examples of What May be Difficult	ISO 9999 class	Technologies (Low to High-Tech) (Note, many fit into multiple categories)
<p>Emotional (b152)</p>  <p>Specific mental functions related to the feeling and affective components of the processes of the mind.</p>	<p>Mood swings, temper outbursts, anxiety attacks</p>	<p>Socially expected and appropriate behaviors, has "meltdowns"</p>	<p>05.12.18 Assistive products for training in problem solving</p>	<p>Noise-canceling headphones, soft music players, alternative lights, vests that apply deep pressure. Snoezelen Multi-Sensory Environment [http://www.snoezelen.com]</p>
<p>Thought (b160)</p>  <p>Specific mental functions related to the ideational component of the mind.</p>	<p>Incoherent thoughts and delusions, illogical thinking</p>	<p>A sequence of tasks that require logic and planning, following through with a plan.</p>	<p>05.12.06 Assistive products for training in sequencing; 05.12.12 concept development, 05.12.15 classification</p>	<p>Visual Assistant [https://store.ablelinktech.com/store.php?cm=200&rn=339&action=show_detail], Community Integration Suite [https://store.ablelinktech.com/store.php?cm=200&rn=329&action=show_detail], Pocket Endeavor [https://store.ablelinktech.com/store.php?cm=204&rn=375&action=show_detail], COGKNOW [http://www.cogknow.eu]</p>

While for many, technology is the answer...



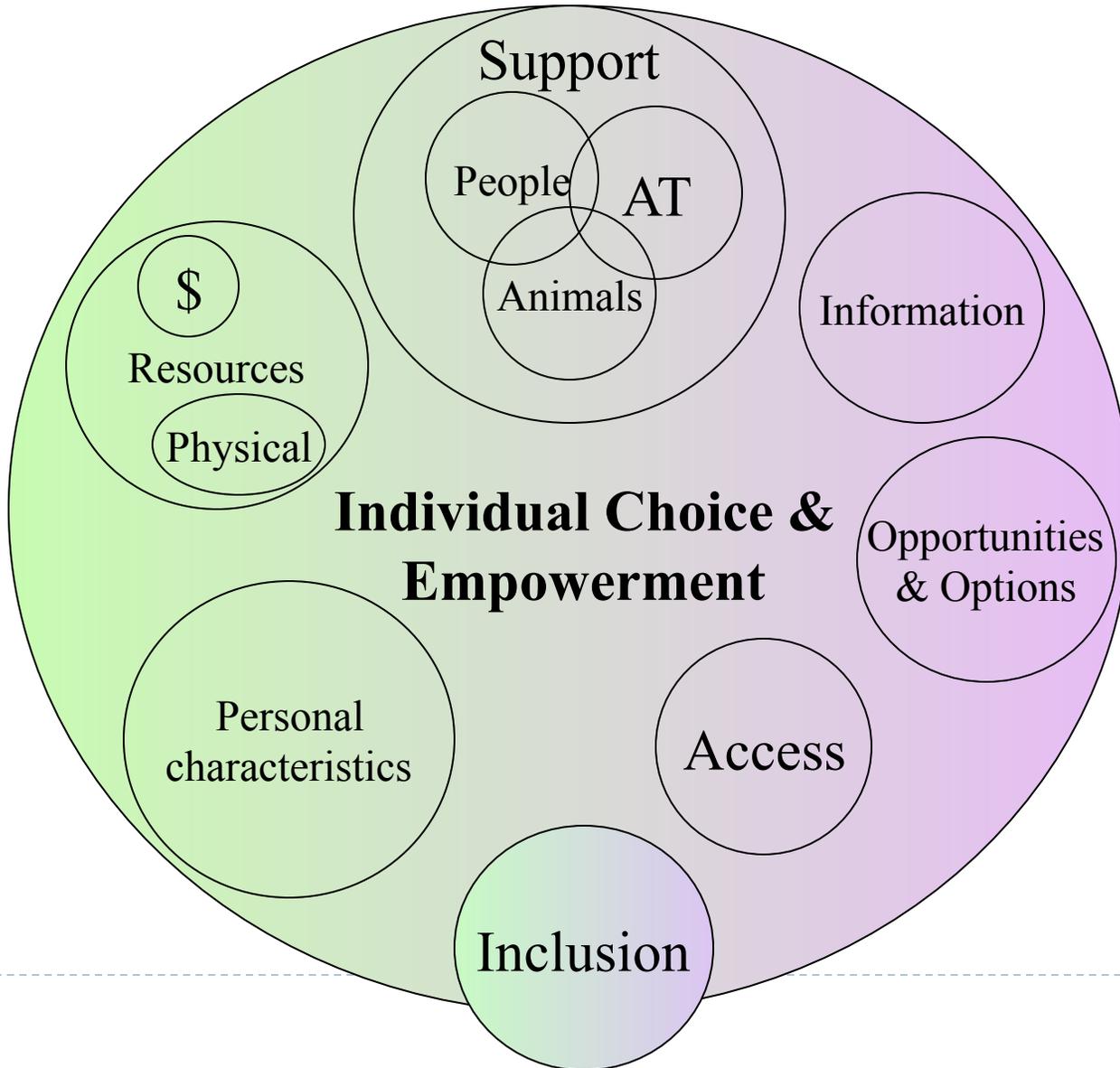
Technology is the Answer... that may not be the question



Rather, the questions consumers have are: *How can I...*

- *Feel more self-confident*
- *Be autonomous, listened to, respected*
- *Participate/contribute as I wish in a variety of roles and activities*
- *Achieve a high quality of life and sense of well-being*

Being Informed and Being Heard: Identifying, then communicating, preferences and priorities



Facts

- ▶ There are an increasing number of people with disabilities living in the U.S.
- ▶ Most people with disabilities who want to work are unemployed.
- ▶ In spite of the AT Act state projects and resources such as AbleData, many providers and consumers lack confidence that they know the most current AT products from which they can choose.
- ▶ They do not have a process to follow to guide them into matching consumers with the most appropriate technologies for their use.

One statistic hasn't changed in over 20 years...

About 1/3 of AT devices are unused or discarded. This represents waste in...

- \$
- Therapist / Provider time
- Participation/contribution of the consumer in school, work the community

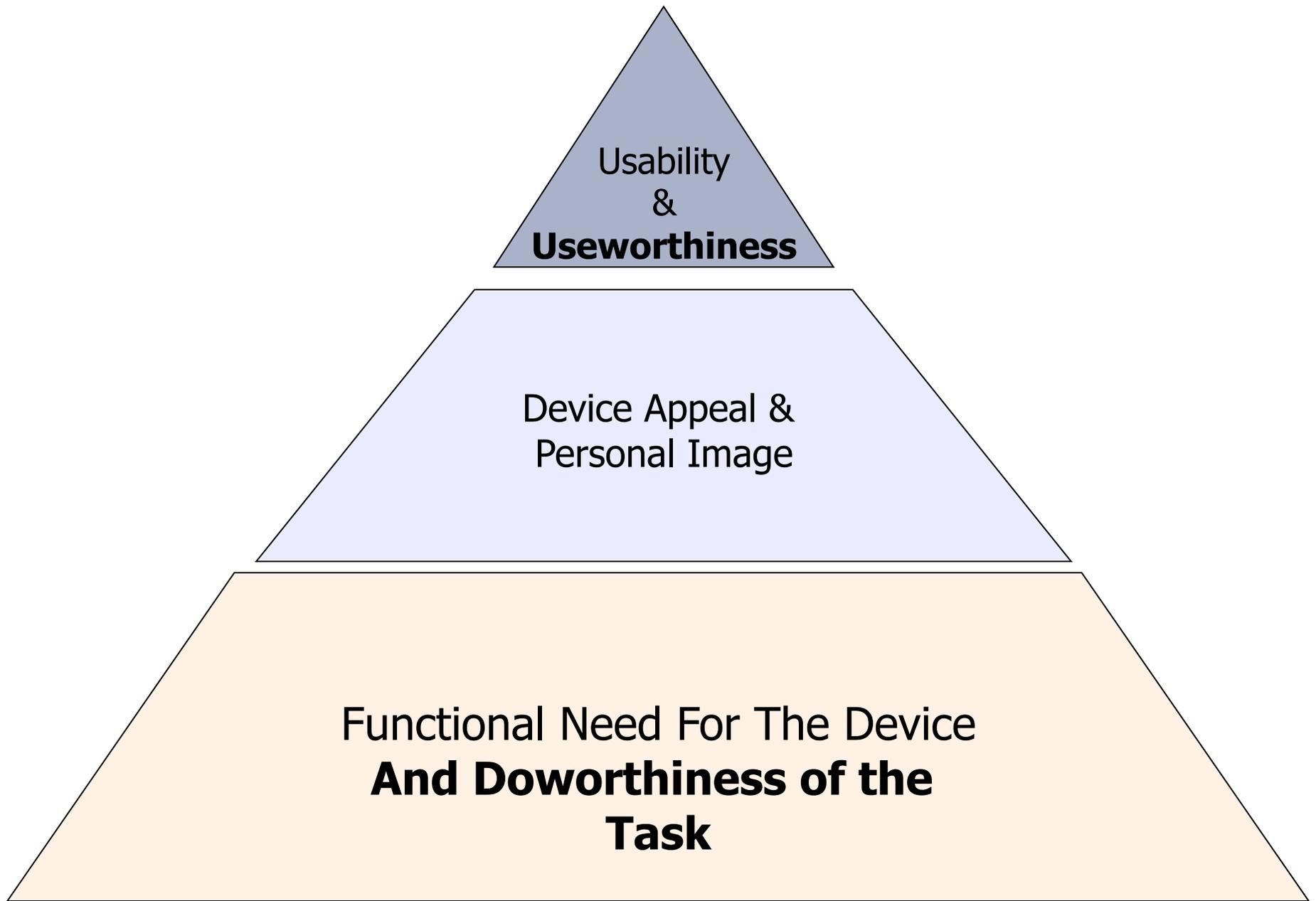
When we see device non-use or discard, it usually arises from...

A poor match of person and
technology !

Targeted



Solutions



SO...

It's **NOT** about the product or the device.

It **IS** about its usefulness, its value.

It's about its **MATCH TO THE PERSON,**
not vice versa.

Rogers' *diffuson of innovation*?

- It must be usable and useworthy!

Device attributes?

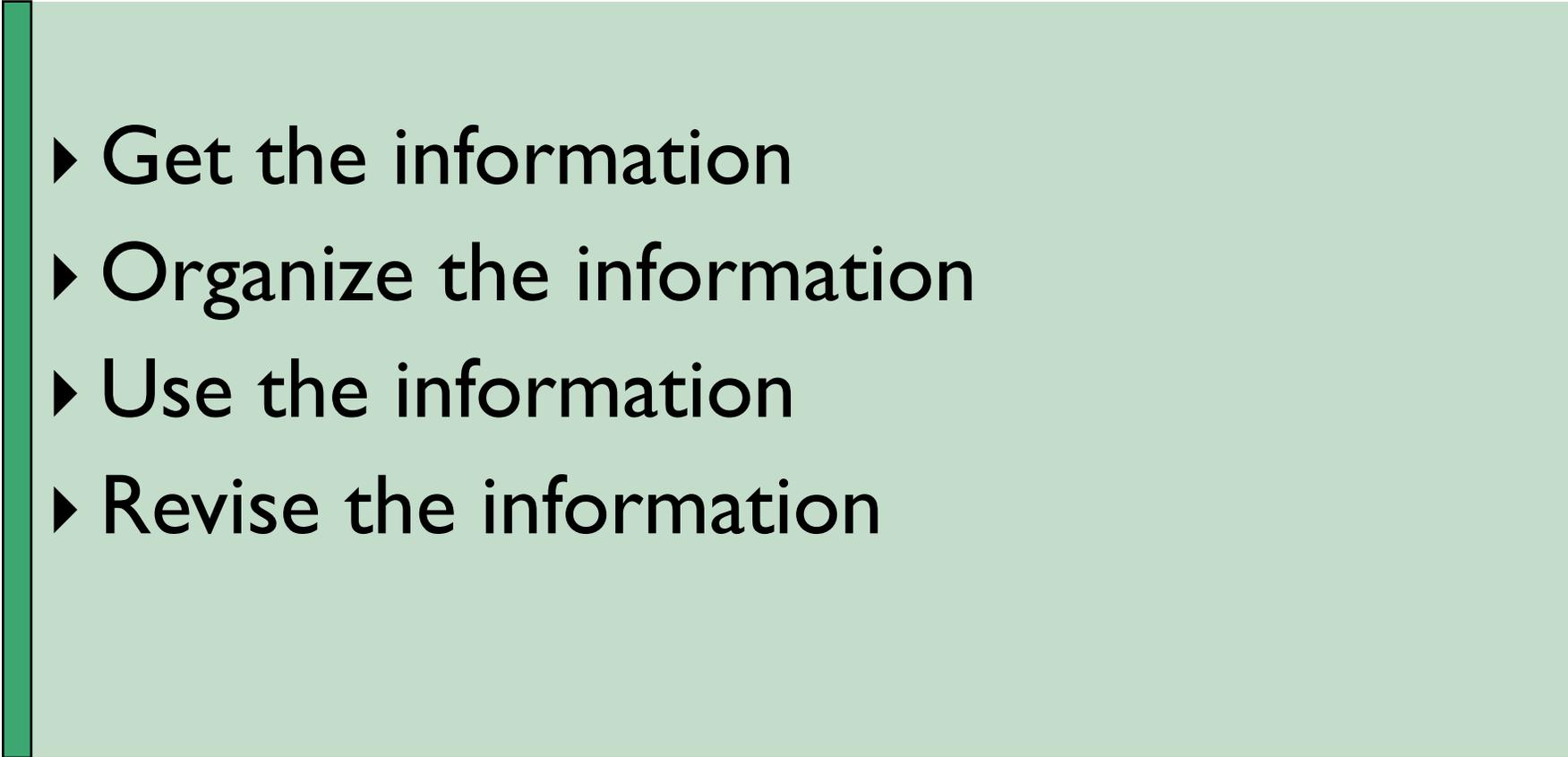
- ▶ Whatever makes it useful and useworthy!

Too many people **STILL** don't get this –
Consumers do, though!

But not enough people are listening to them.



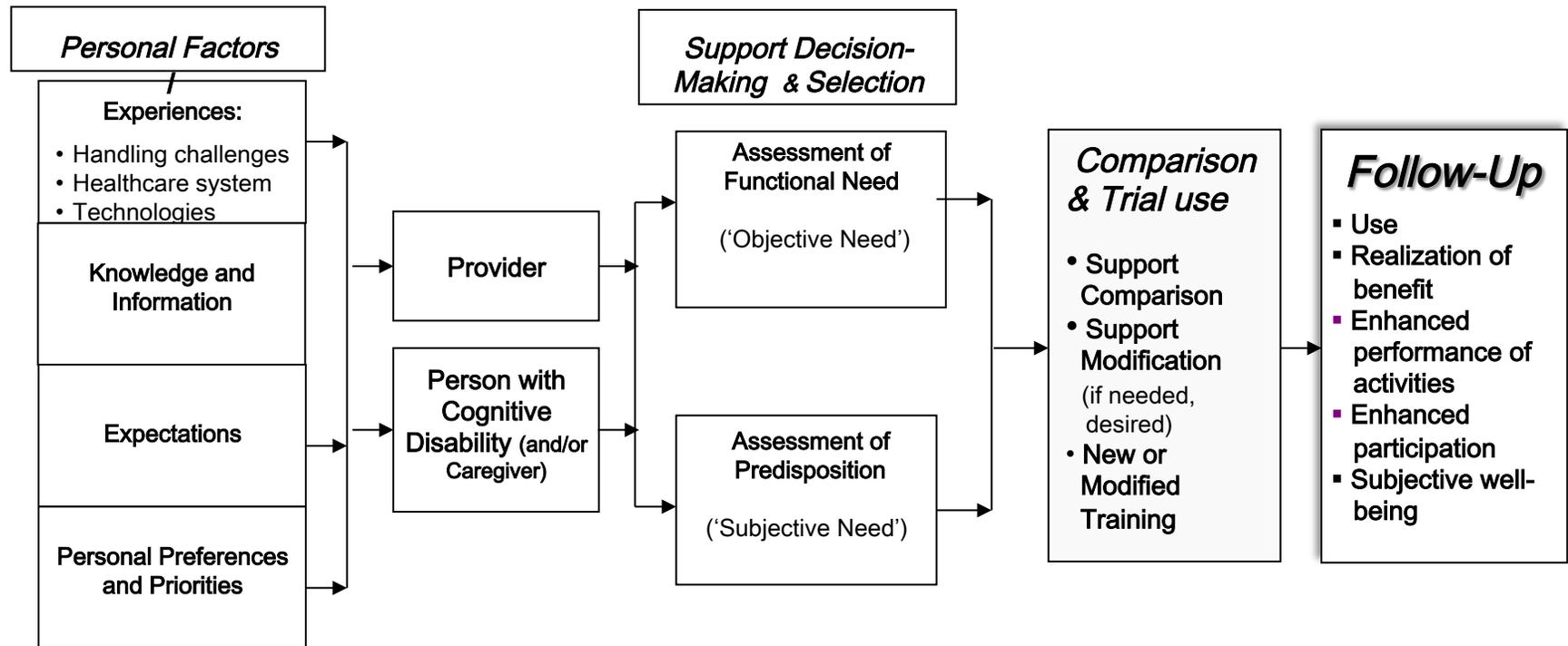
Find out what the user wants...

- 
- ▶ **Get the information**
 - ▶ **Organize the information**
 - ▶ **Use the information**
 - ▶ **Revise the information**

Support (AT and CST) Selection Framework

Environmental Factors

- Availability of Products
- Affordability of Products
- Availability of appropriate professionals
- Opportunities and services
- Cultural and Financial Priorities
- Legislation & Policy
- Attitudes of Key Others
- Support from Family/Friends & Significant Others
- Financial Assets



Adapted from Scherer, M., Jutai, J., Fuhrer, M., Demers, L. & DeRuyter, F. (2007). A framework for modeling the selection of assistive technology devices (ATDs). *Disability and Rehabilitation: Assistive Technology*, 2(1), 1-8.

First ever *World Report on Disability* by WHO and the World Bank:

Ensure maximum consumer choice and control

- ▶ Consumers are involved in **decisions on the type of support** and direct the care tasks wherever possible rather than being a passive recipient of care.
- ▶ **Services are individualized** and flexible rather than “one size fits all” agency-based and controlled services. Develop an individual care plan.
- ▶ **Develop sound and fair disability assessment criteria and procedures**, focusing on support needs to maintain and improve functioning.
- ▶ **Use ICF as a guiding framework in developing disability assessment criteria.**
- ▶ **Cover the broad array of ICF domains** – impairments, activity limitations and participation restrictions, related health condition, environmental factors.
- ▶ **Measures of the lived experience of disability need to be coupled with measurements of the well-being and quality of life of people with disabilities.**
- ▶ **Base interventions on sound research evidence.**
- ▶ **Monitor and evaluate outcomes.**

UN's Convention on the Rights of Persons with Disabilities

Article 26 - Habilitation and rehabilitation

To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes **BEGIN AT THE EARLIEST POSSIBLE STAGE, AND ARE BASED ON THE MULTIDISCIPLINARY ASSESSMENT OF INDIVIDUAL NEEDS AND STRENGTHS.**

World Report on Disability:

Traditionally, rehabilitation outcome measures have focused on the individual's impairment level. More recently, outcomes measurement has been extended to include individual activity and participation outcomes (34, 35). (WHO, 2011, p. 97)

34. Scherer MJ. Assessing the benefits of using assistive technologies and other supports for thinking, remembering and learning. *Disability and Rehabilitation*, 2005,27:731-739. doi:10.1080/0963828040014816 PMID:16096225

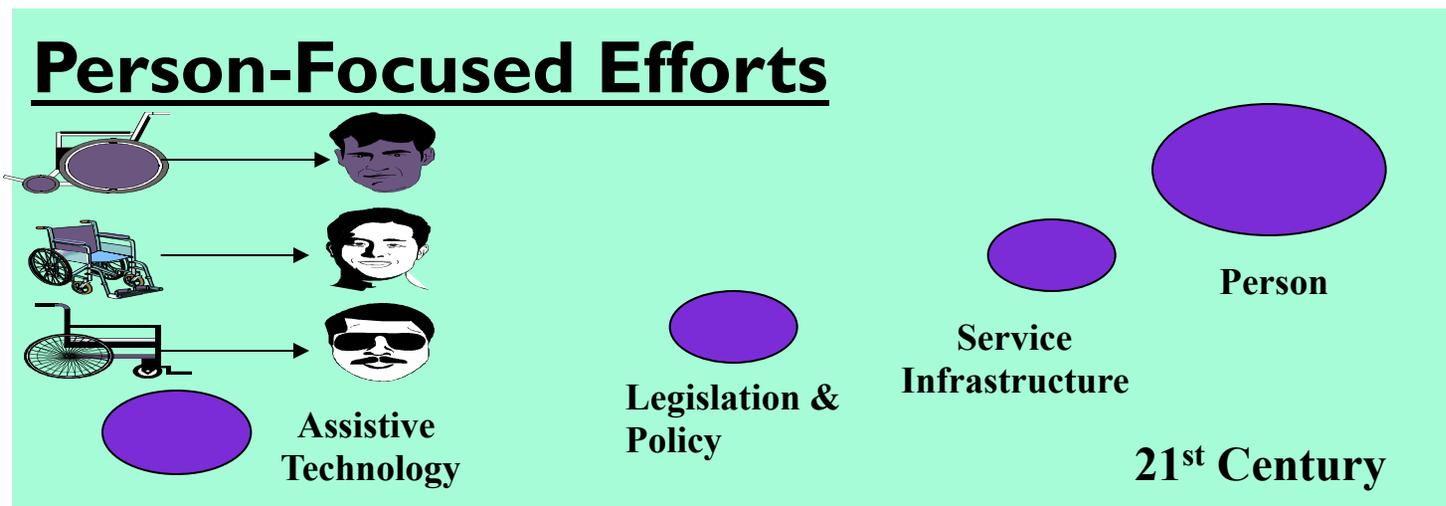
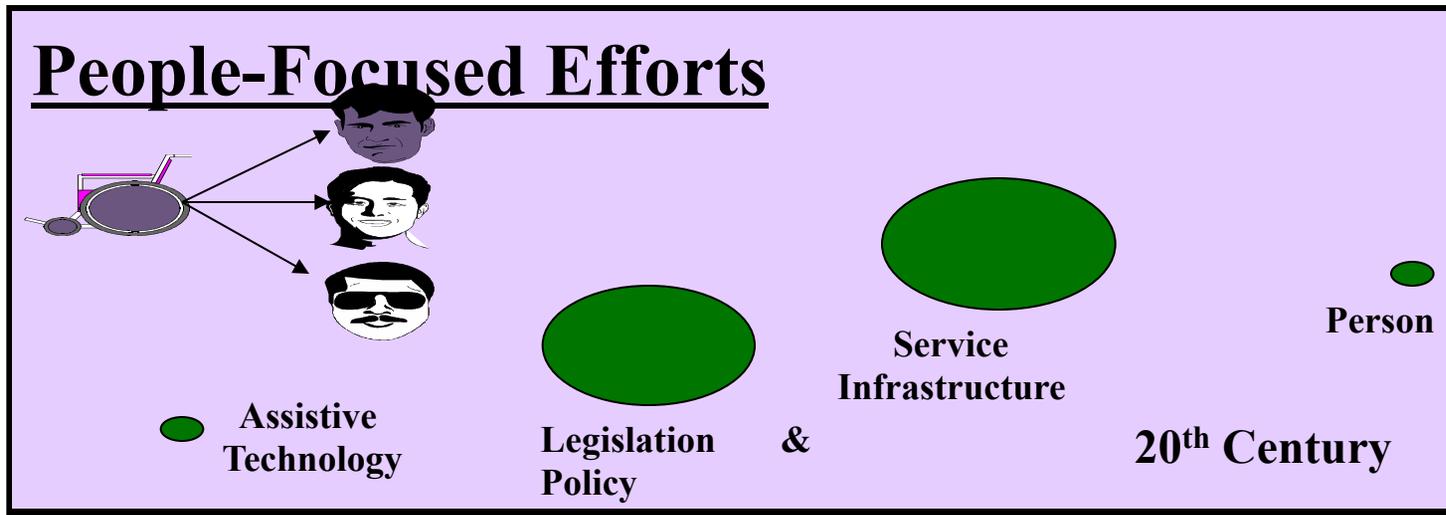
35. Scherer MJ et al. Predictors of assistive technology use: the importance of personal and psychosocial factors. *Disability and Rehabilitation*, 2005,27:1321-1331. doi:10.1080/09638280500164800 PMID:16298935

The Change in Emphasis from People to Person

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Scherer MJ. (2002). The change in emphasis from people to person: introduction to the special issue on assistive technology. *Disabil Rehabil.* 24(1-3):1-4.

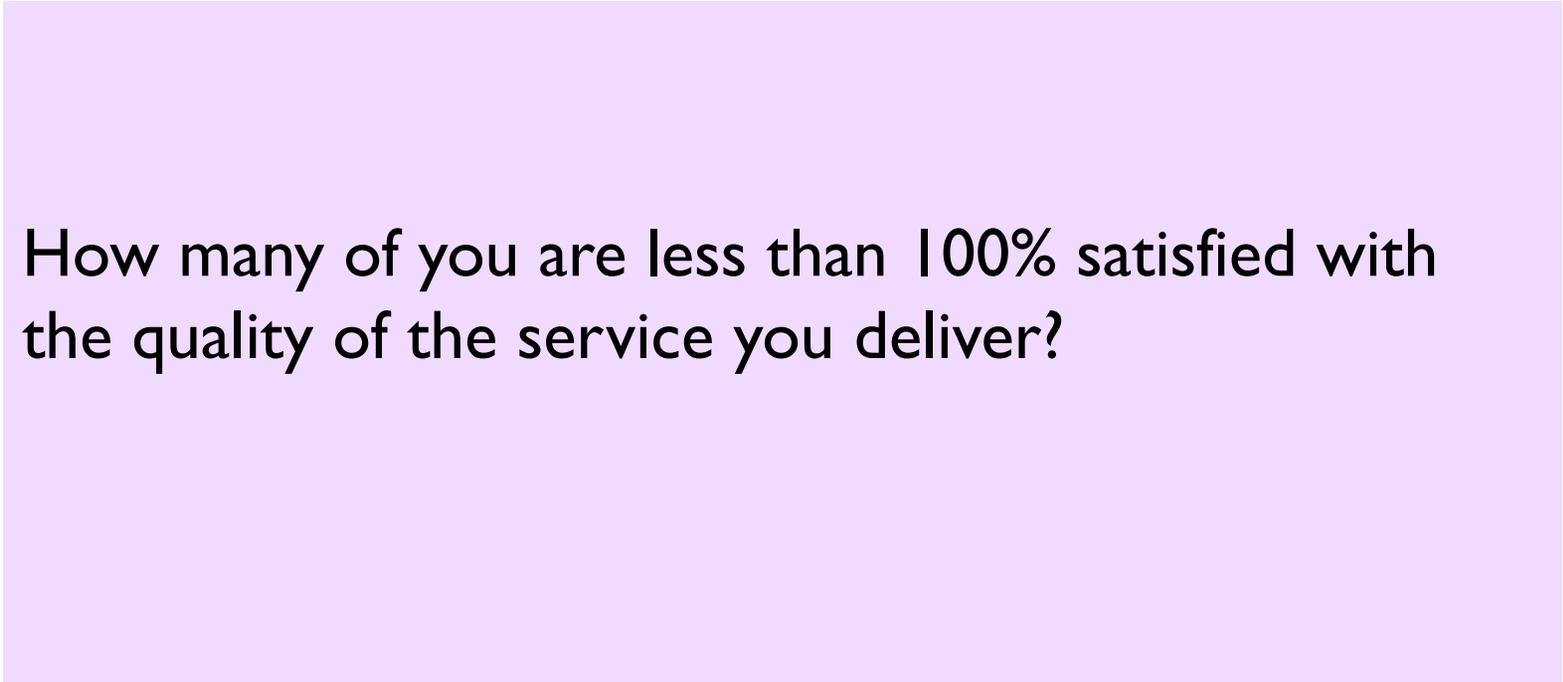
How many of you are consumers/
purchasers of a device within the last
year?

How many of you are less than 100% satisfied with
the device or service delivery?





How many of you are AT providers?



How many of you are less than 100% satisfied with the quality of the service you deliver?



How many of you are AT designers or manufacturers?

How many of you are less than 100% satisfied with the quality of the product you'd like to market due to regulations, etc.?

How much of the quality of your
service delivery is interfered with by

THE SYSTEM

???



**How much longer are we going
to take this????**



Edvard Munch, The Scream, 1893



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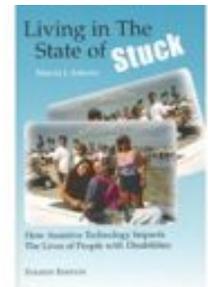
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What do we do????

?



**There ain't nothin' worse
than being stuck.**



--- Butch in *Living in the State of Stuck: How Assistive Technology Impacts the Lives of People with Disabilities*, 2005

ASSISTIVE TECHNOLOGY

SERVICES any service that directly assists in the selection, acquisition, or use of an assistive technology device.



However...

- ▶ Providers say they do not have the time and support –it’s not a priority!
- ▶ Managers have limited resources and focus on cost-effectiveness and cost-efficiency -- they go for “a minimum data set.”
- ▶ We need balance among
 - ▶ consumer needs and preferences
 - ▶ provider needs and preferences
 - ▶ quality service delivery and
 - ▶ cost-effectiveness and cost-efficiency

Think of these as the four tires on a car....

Flatten any 1 of 4 tires and the vehicle is **stuck.**



Questions? Comments? Thoughts?

- What does interagency collaboration on policy objectives need to address?
Going beyond discipline-specific practice guidelines to a shared standard of service?
- How can interagency collaborative research help inform policy objectives?
What and where are the barriers?

