Do It Yourself for People With Disabilities

Etech 2009

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DIY for PWD: Disability & Invention

- Apply principles of:
  - DIY
  - Open Source
  - Disability Rights
  - Universal Design
    - Typewriter, 1843
    - Jaccuzzi – arthritis
    - Oxo tools
    - Good for everyone!

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DIY for PWD: Intro

• Take apart issues around disability tech
• Market & demographics
• Easy hacks
• intermediate hacks
• Political history
• Big international projects. Complex.


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DIY for PWD: Simple ideas

- The Tennis Ball Walker
- Common
- Simple
- Cheap
- Effective
- Noticeable
- Still necessary!

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DIY for PWD: Complicated!

- International issues
- Language barriers
- Medical, orthopedic
- Laws, regulations
- Manufacturing
- Market: Import/Export
- Local Industry
- Training, repair
- Human rights

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DIY for PWD: Why we need open info, online

- People adapt by giving up activities
- Where to get info, equipment?
- Medical authority
- Charity model
- Consumer model
- Inventions and DIY

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DIY for PWD: Demographics

- 11M-55M pwd in U.S.
- 4%-18% of population
- 55M “some” disability
- 35M severe disability
- 11M need help with daily living activities
- Plus institutionalized
- This % is growing fast
- You will likely be a PWD for at least 8 years.

  - Yes, you. And don't say that you'll kill yourself first.

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DIY for PWD: Market for Wheels

- 2.7 M use wheelchair
- 9.1 M walker/crutch
- 20.9 M ride bikes
- Bikes: $5B
- Wheelchairs: >$3.2B
- Growing. 5B in 2011.
- Huge market!
- Competition fierce.
- Big global companies.

HokeySpokes.com. Good for wheelchairs!

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DIY for PWD: Easy hacks

- Holding things
  - Helps grip, dexterity
  - Rubber bands
  - Binder clips
  - Corks
  - Bike handle tape
  - Rubber dip
  - Split tubing

Handmade Helps for Disabled Living, Stuart E. Grainger, 1981.
A fantastic book.
DIY for PWD – Easy hacks

- Carrying things
  - Cross-strap backpack
  - Open tote bags
  - Crutch pockets
  - Travel mugs, bottles
  - Duct Tape!
  - S-hooks for groceries
  - Baby carrier on walker
DIY for PWD: Easy hacks

- Information!
  - Labelling tape (Dymo)
  - Control language for voice activation
  - Example: Use another human language for a meta-language to control devices.
  - Address label on cane (Simple, brilliant)
Easy Hacks: Sports!

- Haddyrs bike and crutch hack
- $13 at hardware store
- Gasket, hose clamps, pipe

Don't assume what people are and aren't capable of doing. Abilities vary widely, sometimes in the same person from day to day.
DIY for PWD: Easy Hacks

- Make it cool
- Fashion, pride, identity
- Blinky lights
- Flames and flowers
- Stickers, stencils
- Customizability

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DIY for PWD: Easy hacks

- Tips, how-tos, simple craft, don't need special tools
- For solo DIY or with helper
- Diagnosis-specific newsletters, patient groups, and sites
- Individual doctors, physical or occupational therapists
- Wikis: Wikihow, Instructables, Disapedia
- Blogs, Forums: Wheelchair Junkie

- Problems:
- Make it once, patent, sell, keep info private or very limited

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DIY for PWD: Intermediate Hacks

- DIY home mods.
- Infrastructure change
- Strength, special tools
- Example: offset door hinges
DIY for PWD

- Miguel Valenzuela – Lift Assist inventor
- Toilet lift
- Hydraulic only
- Can force people into institutions
- $100 from pvc pipe
- On personal (abandoned) blog
- What to do with idea?

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DIY for PWD: Intermediate Hacks

- Mobility!
- Speedy Kitten is speedy
- K'nex
- Part time use
- Geocities, ~1998

- A mobility device like a wheelchair, crutches, or walker may, or may not, require special medical knowledge. It depends!

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DIY for PWD: Intermediate Hacks

- Speedy Kitten's cart
- Legal Disclaimers
  - Example: “K’NEX® Industries, Inc. does NOT supply schematics or any information related to applications of the use of their toys for these purposes. The designs and ideas are from Dr. Jeszenka, owner of Speedy.”
- Medical warnings
- Trained orthopedic vets only!

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Legal fears hurt information spread.

People are afraid to share information freely on this subject, where they aren't afraid to share other similar kinds of information.

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Nice URL, dudes.
DIY for PWD: Intermediate Hacks

- Arts for All painting
  - golf caddy carts
  - rotisserie motors
  - lawn mower frames
  - attach to walkers, chairs
  - Great inventions!!
  - Patents + not very good online store = limited and local implementation

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DIY for PWD: Intermediate Hacks

- How medical is your device?
- Bikes. Strollers. Office Chairs.
- Lawsuits. Problems with the ADA. Can be protective and useful.
- Mystification, fear, obfuscation, control
- Disability rights

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DIY for PWD: Intermediate Hacks

Example: Ramps

- Nonprofits, state/county governments.
- Detailed blueprints
- Regulations, contractors
- Materials, cost
- Volunteers
- Online! Rare!

Metropolitan Center for Independent Living, Minnesota Division of Rehabilitation Services, Multiple Sclerosis Society and United Handicapped Federation. Ford Foundation award, 1991.
DIY for PWD: Intermediate hacks

- Require particular technical skill, strength
- Require extra labor. Mobilize volunteers.
- Home modifications
- Sewing, knitting, advanced textile skill
- Metalworking, electronics, engineering
- Classes, workshops, co-ops, TechShop, community colleges
- Need more than a How-To
- Need community!

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DIY for PWD: Political History

Let's look at problems:

- In 60s, 70s, no integration, no curb cuts, infrastructure
- Forced institutional living
- Medicare “Homebound Rules”: house arrest
- Forced sterilization
- Ashley treatment (2007)
- Assisted suicide

Ed Roberts

Independent Living Movement

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The Black Panther Party and LGBT activists brought food and medicine to the hundreds of disabled people who occupied the Federal Building for 45 days until Section 504 was signed into law.
DIY for PWD: Political History

- Blogs, activism are on the rise
- Many good local organizations
- Political change still needed

- 2000s: Ed Roberts Campus in Berkeley
DIY for PWD: Political History

“The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect.”

- Tim Berners-Lee
DIY for PWD: Global Hacks

- REMAP: A big nonprofit that does a lot of good
- PWD, meet Inventor.
- A single person is helped.
- But . . .
- Information black hole. Why?
- Charity model.
- Lack of online savvy.
- Lack of a way to patent less defensively
DIY for PWD: Global hacks

- Free Wheelchair Mission
- $52 Wheelchair
- Made in China
- Ship to Uganda
- Problems
  - Undermine local industry
  - Product not sturdy
  - Training, fixing is short term only.

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DIY for PWD: Global hacks

- Whirlwind Wheelchair International
- Multiple NGO, multi country involvement
- Plans with local agencies and industry
- Empowerment for PWD. Ongoing.
- Deep followup in community.

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DIY for PWD: Global Hacks

- CIR: Center for International Rehabilitation
- Instructables how-to has the basics!
- Prosthetic Arm from a Soda Bottle and PVC pipe
- More info, training, videos, online and RL.

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DIY for PWD: Global Hacks

- The technique was developed by the Center for International Rehabilitation (CIR) in Chicago. The CIR is a non-profit organization that works in underserved and conflict-affected regions worldwide to meet the needs of people with disabilities.

- This work was funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133E030017.

- The plastic soda bottle prosthesis is designed for light-duty activities and should be fabricated by individuals with proper training in prosthetics and related biomechanics.

- Also, Wheelchair distribution/repair/training

- Prosthetic soda bottle leg for baby elephant

Legal concerns. Don't try this at home! Except when you do! Just put it out there, have some guts.

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DIY for PWD: Where's the information?

- Organization archives
- File cabinets
- Alexandra Enders, proposal for digitization project
- Private info is lost
- Need it in public domain

Also, in people's heads; ask them. Everyone with disabilities that I've met has invented something. We have to!

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DIY for PWD: Hacks Need Communities

- Sometimes you need to see it to think of it
- PWD are often isolated physically.
- Need community for serendipity, invention
- The more complex the idea, the deeper community ties you need.
DIY for PWD: Online communities

- Disapedia, Wheelchair Junkie (one person)
- GimpGirl group
- OneSwitch.org
- Mailing lists (Silos!)
- Blog carnivals, OuchUK
  - Disability Studies blog
- Disaboom
  - Corporate, inauthentic

WARNING: While every effort has been made to ensure that all information on this site is accurate, it is for informative purposes and shouldn't be used as an alternative to professional care and instruction. The photos and information on this site may not reflect individual products, and you should consult your mobility professional and product owner's manual to determine your product's capability. Appropriate professional advice should be considered before using any techniques or equipment discussed on this site.
DIY for PWD: Opportunity!

- What's stopping people?
- Cultural differences
- Fear of mortality, pain
- Licensing. Profit
- Forums that aren't controlled by government, academic, or corporate institutions
- Fear of liability
- Are we not hackers?

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DIY for PWD: Opportunity!

- Space owned by large clumsy bureaucratic institutions.
- Growing market. Lazy incumbents.
- Biz opportunities for tech, hardware, web?
- Disruptive companies will kick butt

Trekinetic all terrain wheelchair, 2008
DIY for PWD: Opportunity!

- Team up with accessibility consultants, disabled people, you will learn about practical hacking
- Pay them
- Keep it real!
- Make it cool!

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DIY for PWD: The Future

- Tactile Maps
- Mashup, maps for visually impaired
- Lighthouse for the Blind, SF
- $15 for businesses
- Free for CA residents with visual impairment
DIY for PWD: The Future

- Why do wheelchair brakes suck?
- 3D Printing + open source HW + Copyleft
- Run a contest, open source all entries
- 3D Printers will be increasingly common
- Print new brakes at the hardware store
- This will be awesome!

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Partial List of References and Photo Credits.


http://www.independent.co.uk/life-style/gadgets-and-tech/features/trekinetic-reinventing-the-wheelchair-858190.html?action=Popup&ino=1 The Independent; Photo by Carlos Jasso


http://www.bikeleague.org/media/facts/#how_many National Survey of Pedestrian and Bicyclist Attitudes and Behaviors was sponsored by the US Department of Transportation’s National Highway Traffic Safety Administration (NHTSA)


Abledata DIY. http://www.abledata.com/abledata.cfm?pageid=113582&orgid=109086

U.S. Census Bureau, Americans With Disabilities: 2005