

limited use of his hands. The design process and the inventions were analyzed using qualitative methods. Results showed that the children's inventions differed significantly from the designs of current AAC technologies. The inventions integrated multiple functions such as communication, social interaction, companionship, play, artistic expression, and telecommunication, and provided dynamic contexts to support social interactions with others, especially peers. The children described the systems as companions and utilized innovative names, bright colors, lights, transformable shapes, popular themes, humor, and amazing accomplishments, to capture interest, enhance appeal, build self-esteem, and establish a positive social image. The systems were easily personalized to reflect the user's age, personality, interests, and preferences. Implications for the design of AAC technologies and future research and development are discussed.

Stowe, M., Turnbull III, H. (2007) **Looking to the future: Intellectual and developmental disabilities in the genetics era.** *Journal on Developmental Disabilities*, 13(2), 1-64. [NARIC Accession Number: J54457](#). Project Number: H133B031133.

Abstract: Article focuses on the need for people with disabilities to become more aware and more involved in human genetics issues. By identifying the genetic factors that contribute to or cause disability, scientist may be able to create better ways to identify, treat, prevent, or even cure biological causes of intellectual or developmental disabilities. Following a brief history of the human genome project, the implications of genetic research and technology development are discussed in 6 areas: health and medical implications, evolving attitudes and perceptions, effects on autonomy and self-determination, cultivating discrimination or equality, designing lives and the public health, and effect on the family and society. The authors also describe what limited actions have been taken in law and research to address the concerns and foster the benefits of genetic research. The article concludes with recommendations for disability community involvement in human genetics.

Ravesloot, C. (2007) **Tele-health promotion for rural people with disabilities: Toward a technology assisted peer-support model.** *Rural Disability and Rehabilitation Research Progress Report #37, September, 1-4.* [NARIC Accession Number: O17023](#). Project Number: H133B030501.

Abstract: Study examined the feasibility of an Internet health promotion program for people with disabilities who live in rural areas. Feedback from people with disabilities was incorporated into the design of the program, which delivered curriculum using audio-supported slide shows. Participants for the program were recruited by mailing program information to centers for independent living (CILs) to disseminate to their consumers. Despite the use of participatory action research procedures in developing the intervention, very few CIL consumers explored and later accessed the online program. Based on recommendations, procedures and materials are being developed to combine peer support with the online program to use in the outreach efforts to increase consumer participation. **This article is available in full text at [naric.com](#).**


Favuzzi, T., Dinse, P. (2007) **A year of action: Creating change together., 1-75.** [NARIC Accession Number: O17097](#). Project Number: H133A010702.

Abstract: Report reviews the actions taken by community researchers from independent living centers across California in response to the findings of the Community Research for Assistive Technology (CR4AT) project. CR4AT is a five-year, community-based research program using a participatory action research model to collect data on access to and use of assistive technology (AT) to improve the lives of people with disabilities. Action teams spent a year creating change to address issues related to mass marketing of AT; AT public policy issues including health care, eligibility, and funding; the education of the business and disability communities; and outreach to Latinos with disabilities. **This article is available in full text at [naric.com](#).**

(2007) **Community research for assistive technology: Project abstract. , 1-2.** [NARIC Accession Number: O17221](#). Project Number: H133A010702.

Abstract: Fact sheet outlines procedures for the Community Research for Assistive Technology (CR4AT) project. CR4AT is a five-year, community-based research program using a participatory action research model to collect data on access to and use of assistive technology (AT) to improve the lives of people with disabilities in California. **This article is available in full text at [naric.com](#).**

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NIDRR Grantees on the Cutting Edge

Center for Strategic Capacity Building on Minorities with Disabilities Research
University of Illinois at Chicago (H133A040007) led by Fabricio E. Balcazar, PhD.
Shelley Reeves, Project Officer.

Abstract: The Center for Capacity Building on Minorities with Disabilities Research (CBMDR) increases the capacity of community-based organizations (CBOs like Centers for Independent Living and other agencies) and State Vocational Rehabilitation (VR) Agencies to document the impact of their programs and develop culturally competent services. Center staff conducts participatory research and demonstration projects in collaboration with interested agencies, engages in active dissemination efforts, and provides state-of-the art training and technical assistance on cultural competence to professionals and researchers in the field. The Center utilizes a participatory program evaluation model which actively involves consumers and agency staff in the process of identifying service needs, selecting program goals, developing a logic model for success, and implementing and evaluating change efforts to address critical needs and improve services. From this perspective, participating agencies develop their capacity for effectively using consumer input and program data to identify research questions and methods to improve services. In addition, research projects examine various aspects of theory, methodology, measurement, and dissemination of information involving the study of underrepresented minorities with disabilities.

Find out more at: [www.disabilityempowerment.org](#)

Innovative Knowledge Dissemination and Utilization for Disability and Professional Organizations and Stakeholders
Boston University (H133A050006) led by Marianne Farkas, ScD. Pimjai Sudsawad, ScD, Project Officer.

Abstract: This project develops, tests, and applies a process of research standards development, implementation, and related information dissemination strategies that allows end-users in the rehabilitation field to make informed choices based on the perceived utility of the research available, and in doing so, promote utilization of rehabilitation research. The project has six specific goals: (1) Producing quality standards for rating rehabilitation research rigor and meaning. A broad range of experts and various stakeholders participate in consensus building regarding adapting existing standards for rating research rigor, and create standards for meaning (perceived relevance). (2) Project staff, along with NIDRR staff, professional and constituent organizations, and other Knowledge Translation projects assist in developing standard topic selection criteria and in selecting topical areas for information products. (3) Producing relevant information products describing the quality and

“Essentially Participatory Action Research (PAR) is research which involves all relevant parties in actively examining together current action (which they experience as problematic) in order to change and improve it.”

-What is Participatory Action Research (PAR)? Wadsworth, Y. (1998). Read the full discussion: [www.scu.edu.au/schools/gcm/ar/ari/p-ywadsworth98.html](#)

Please note: These abstracts have been modified. Full, unedited abstracts, as well as any available REHABDATA citations, are available at [naric.com](#).

Thousands of additional resources on these topics are available from NARIC's resource pages at [www.naric.com/public](#)

Participatory Action Research may be found in each of NIDRR's priorities, particularly in Participation and Independent Living and Capacity Building for Rehabilitation Research and Training.

implications of rehabilitation research studies based on the developed standards. Constituent organizations participate in developing dissemination plans to translate research syntheses in the identified topical areas into information products relevant for appropriate constituencies. (4) Creating and testing a prototype interactive website, The Right to Know Clearinghouse, to implement innovative dissemination strategies for key groups. (5) Evaluating the output, perceived utility, and outcomes of the Knowledge Translation project using the NIDRR logic model. Evaluated outcomes include an increase in awareness of research among constituency groups, an increase in understanding of research rigor and meaning among those groups, and an increase in the use of research information by end-users. (6) Disseminating the project's findings to stakeholders.

Rehabilitation Research and Training Center for Recovery and Recovery Oriented Psychiatric Rehabilitation for Persons with Long-Term Mental Illness *Boston University* (H133B040026) led by Marianne Farkas, ScD; E. Sally Rogers, ScD. Bonnie Gracer, Project Officer.

Abstract: This project focuses on the concepts and dimensions of recovery and the various factors that inhibit and facilitate recovery from long-term mental illness by a comprehensive and meritorious set of research projects and training, technical assistance, and dissemination activities. The research and the training, dissemination, and technical assistance programs are organized into the following three programmatic areas of investigation and development: concepts and dimensions of recovery, factors enhancing recovery, and factors inhibiting recovery. Research projects use a participatory research process with significant input from consumers and other stakeholders, and culminate in dissemination, training, or technical assistance activities to maximize the input of the research program. The Training, Dissemination, and Technical Assistance (TDTA) projects are designed to provide exposure, experience, and expertise levels of knowledge transfer, and increases the likelihood that researchers, service providers, and others use the cumulative knowledge developed by the RRTC.

Find out more at: www.bu.edu/cpr/research/ongoing/rtc2009/index.html

Rehabilitation Research and Training Center on Traumatic Brain Injury Interventions *Mount Sinai School of Medicine* (H133B040033) led by Wayne A. Gordon, PhD. A. Cate Miller, PhD, Project Officer.

Abstract: The research program includes two randomized clinical trials and two projects supportive of better everyday interventions and better research. It also implements participatory action research-based analyses of high priority areas, including meta-analyses if appropriate. In addressing improved outcome measurement, analysis focuses on the PART instrument, a measure of participation currently being tested within eight TBI Model Systems. This analysis focuses on creating a subjective approach to serve as a complement to the PART's current focus on objective assessment. A major focus of the RRTC is placed on capacity building of clinical and research professionals to address the need for better day-to-day interventions in the lives of people with TBI.

Find out more at: www.tbicentral.org

Advanced Rehabilitation Research Training Program *Mount Sinai School of Medicine* (H133P050004) led by Mary R. Hibbard, PhD. Dawn Carlson, PhD, MPH, Project Officer.

Abstract: This Advanced Rehabilitation Research Training Program increases research capacity by training ten doctoral level professionals interested in pursuing research careers in rehabilitation of individuals with traumatic brain injury (TBI) and spinal cord injury (SCI). In addition to expanding their research expertise, fellows will increase their knowledge of participatory action research and quantitative and qualitative research methods, and actively participate with an interdisciplinary team of rehabilitation researchers. Fellows are taught approaches to performance management and methods of evidenced-based practice review. Research capacity building of the fellows is facilitated via mentoring on independent research projects and clinical supervision in interdisciplinary research experiences.



Photo Credits: Sachin Godke, India

PAR gives people a chance to direct the research that will effect their world. For more information, Wikipedia has an excellent, well-organized introductory article on PAR at en.wikipedia.org/wiki/Participatory_action_research. It includes full citations and links to additional resources such as the 16 tenets of PAR at www.caledonia.org.uk/par.htm

Where Can I Find More?

A quick keyword search is all you need to connect to a wealth of disability and rehabilitation research. NARIC's databases hold more than 75,000 resources. Visit www.naric.com/research to search for literature, current and past research projects, and organizations and agencies in the US and abroad.



The Cochrane Collaboration lists 3 clinical trials using PAR, including one by the RTC on Disability in Rural Areas at the University of Montana! Their research was used to develop and evaluate the Living Well with a Disability program. (An article on this project is available through NARIC [Accession No J53764]). Visit www.thecochranelibrary.org and search "participatory action research" to look for the whole phrase.

Current Literature - Selections from REHABDATA

Garcia-Inarte, E., Kramer, J. (2008) "Who did what?": A participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities*, 1-13. [NARIC Accession Number: J55009](#). Project Number: H133B031134.

Abstract: Article describes a participatory action research collaboration between a community-based self-advocacy group of people with intellectual disabilities and university researchers focused on building group capacity for advocacy. A focus group, sustained participatory engagement, and a reflexive process were used to gather qualitative and quantitative data over 15 months. The collaboration generated action products, including tools to support advocacy and an accessible action and reflection process. The research findings suggest that the manner in which supports are provided influences the control self-advocacy groups have over decision making and therefore, their capacity for advocacy.

Jurkowski, J. (2008) Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46(1), 1-11. [NARIC Accession Number: J54145](#). Project Number: H133B031134; H133F040031.

Abstract: Article describes Photovoice as a tool for engaging people with intellectual disabilities to actively participate in research affecting programs and policies. Photovoice uses photography to actively include people with disabilities in the research process. An example is provided of a participatory study conducted with Latinos with intellectual disabilities. The benefits and challenges of employing Photovoice with this population are discussed. A second article on Photovoice is indexed in REHABDATA under Accession Number J55013.

Lew, A. (2007) Tales from the front: Lessons of inclusion on a stroke research team. *Topics in Stroke Rehabilitation*, 14(1), 85-87. [NARIC Accession Number: J52083](#). Project Number: H133B031127.

Abstract: Author discusses his experience working as a peer mentor in a stroke research project. His discussion focuses on the benefits he received from participation in stroke rehabilitation research.

Mwachofi, A. (2007) Rural access to vocational rehabilitation services: Minority farmers' perspective. *Disability and Rehabilitation*, 29(11-12), 891-902. [NARIC Accession Number: J52899](#). Project Number: H133G000192.

Abstract: Article examines the need for and obstacles to access to vocational rehabilitation (VR) services for minority farmers. Using a community-based participatory action research approach, farmers were trained to conduct interviews and focus group discussions with farmers and state VR counselors. Results showed a serious lack of information. Farmers were not aware of VR services or how to access them and VR was not aware of farmers' needs. Farmers felt marginalized and afraid that access to VR services would diminish their ability to earn a living on the farm.

Light, J., Page, R. (2007) Children's ideas for the design of AAC assistive technologies for young children with complex communication needs. *Augmentative and Alternative Communication*, 23(4), 274-287. [NARIC Accession Number: J53773](#). Project Number: H133E030018; H133E980026.

Abstract: Study used a participatory design methodology to examine children's preferences and priorities for the design of augmentative and alternative communication (AAC) technologies for children with complex communication needs. Six 10-year-old children without disabilities were provided with drawing and craft materials and were asked to develop prototypes of inventions to support the communication of a young boy who used a wheelchair, was unable to speak, and had