



Volume 12, Issue 1, 2017

reSearch

A collection of research reviews on rehabilitation topics from NARIC and other information resources.

Advocacy, Self-Advocacy, & Self-Determination for Individuals with Disabilities

In this edition of reSearch we explore the topic of advocacy, self-advocacy, and self-determination for individuals with disabilities. Self-determination and self-advocacy are two distinct, yet related terms: Self-determination refers to the right of individuals with disabilities to have full-power over all areas of their lives. This includes the freedom to dictate control over political, economic, and the social context in which individuals with disabilities live, learn, and work; participate in community activities and politics; and socialize. Domains of self-determination may include but are not limited to: Choice-making, decision-making, problem-solving, goal-setting, and self-management (<https://www.waisman.wisc.edu/naturalsupports/pdfs/Self-Determination.pdf>).

Self-advocacy refers to individual with disabilities speaking and acting on their own behalf and may include advocating for the supports and services needed to live a self-determined, inclusive, and independent life within the community (<http://tucollaborative.org/community-inclusion/community-inclusion/self-determination>). Examples of self-advocacy may include: speaking up for one’s self, asking for what one needs, negotiating for oneself, and communicating your needs and/or disability through the written word, and pictures or gestures (<https://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/self-advocacy>).

Individuals with disabilities may choose to build their skills in the areas of self-determination and self-advocacy through education and participation. Service providers, educators, stakeholders, and parents and guardians as well as peer groups may also provide channels for information and skill training related to self-determination and self-advocacy; and may assist in equipping individuals with disabilities with the skills, knowledge, and attitudes needed to assume primary control and responsibility over their lives.

Resources are available online on self-determination and self-advocacy related to a variety of disability types. The recently-completed NIDILRR-funded National Research and Training Center on Psychiat-

ric Disability (NRTC) offers a [series of tools](#) to advance self-determination and person-driven services for use by people with psychiatric disabilities. The National Gateway to Self-Determination provides [information on self-determination](#) related to individuals with developmental disabilities; and a [Research to Practice in Self-Determination Series](#) covering a variety of topics related to self-determination and self-advocacy, employment, health, aging, and more. Finally, the NIDILRR-funded Rehabilitation Research and Training Center on Community Living at the University of Kansas offers a free online training program for college students with disabilities, [Access to Success](#). Access to Success provides information for students with disabilities on their rights and responsibilities under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, requesting accommodations and supports from instructors and institutions, and skills for advocating for themselves. Outside of the NIDILRR community, the Autistic Self-Advocacy Network’s [resource library](#) includes policy advocacy toolkits related to health care, civic engagement, home and community-based services, and specific self-advocacy resources such as the [Self-advocate Curriculum](#), and [Getting and Advocating for Community-based Housing](#).

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This edition of reSearch provides a 10 year “snapshot” of research on advocacy, self-advocacy, and self-determination. This snapshot” presents research related to advocacy, self-advocacy, self-determination, and how it may affect outcomes among individuals with moderate to severe disability. The combined search terms for this edition of reSearch included: Advocacy, Self-Advocacy, Self-Determination, and People with Disabilities. A listing of over 100 additional descriptor terms between the NARIC, ERIC, and the PubMed databases can be found at the end of this document. A search of the REHABDATA database resulted in 32 documents published between 2006 and 2016; and 6 international research that may have been collected by CIRRIE between 2008 and 2012. The ERIC and PubMed database searches resulted in 8 documents between 2007 and 2016, and 13 documents between 2005 to 2017; respectively.

NIDILRR Funded Projects Related to Advocacy, Self-Advocacy, & Self-Determination

In addition to document searches, we searched our NIDILRR Program Database to locate grantees/projects related to advocacy, self-advocacy, and self-determination. While no current projects addressed these topics directly, we identified several on directly-related topics (i.e., community living, participation, transition, and self-management). The search resulted in seven currently funded and eight projects that are no longer active. Project information and their publications are offered as additional resources for our patrons.

The Community for All Project to Develop a Series of Six Online Toolkits to Improve Community Living and Participation for People with Intellectual and Developmental Disabilities

Project Number: 90DP0068
(formerly H133A140063)
Phone: 315/443-1288
Email: wharbour@syr.edu.

Evaluation of “Project TEAM (Teens making Environmental and Activity Modifications)”: Effectiveness, Social Validity, and Feasibility

Project Number: 90IF0032
(formerly H133G120091)
Phone: 617/353-2702
Email: kramerj@bu.edu.
<http://sites.bu.edu/projectteam>.

Motivating Self-Management Through Multi-Media Health Promotion

Project Number: 90DP0073
Phone: 406/243-2992
Email: craig.ravesloot@mso.umt.edu.
<http://www.healthycommunityliving.com>.

MyLife: Development of a Cloud-Based Transition ePortfolio for Individuals with Cognitive Disabilities

Project Number: 90IF0080
(formerly H133G140192)
Phone: 866/573-3658
Email: tkeating@cognitopia.com.
<http://www.cognitopia.com>.

Research and Training Center for Pathways to Positive Futures: Building Self-Determination and Community Living and Participation

Project Number: 90RT5030
(formerly H133B140039)
Phone: 503/725-8313
Email: rtcpubs@pdx.edu.
<http://www.pathwaysrtc.pdx.edu>.

Research and Training Center on Community Living for People with Intellectual Disabilities

Project Number: 90RT5019
(formerly H133B130006)
Phone: 612/624-6328
Email: rtc@umn.edu.
<http://rtc.umn.edu>.

Understanding and Increasing Supported Decision-Making’s Positive Impact on Community Living and Participation Outcomes

Project Number: 90DP0076
Phone: 315/443-9703
Email: pblanck@syr.edu.
http://bbi.syr.edu/projects/Community_Living_DRRP/index.html.

These projects have completed their research activities and are now closed.

Defining Success: Web-Based Transition Training for Students with Traumatic Brain Injury

Project Number: 90IF0063
(formerly H133G130307)
Phone: 541/346-0598
Email: efgreene@uoregon.edu.
<http://www.cbirt.org/our-projects>.

Enabling Self-Determination for People Living with AIDS

Project Number: H133G020217
Phone: 312/996-4973 (Keilhofner),
312/355-2656 (Braveman)
Email: kielhfnr@uic.edu.

The Impact of Interventions on Self-Determination and Adult Outcomes

Project Number: H133A031727
Phone: 785/864-0723
Email: wehmeyer@ku.edu.
<http://www.beachcenter.org>.

Leadership Development of Self-Advocates

Project Number: H133F070013
Phone: 301/608-0949
Email: jcaldw3@uic.edu.

Louisiana's Self-Determination Research Project

Project Number: H133G990169

National Resource Center on Supported Living and Choice for People with Mental Retardation and Developmental Disabilities

Project Number: H133A990001
Phone: 800/894-0826

Pocket Compass: A Palmtop Computer-Based Intelligent Aid for Individuals with Mental Retardation to Increase Independence and Self-Determination in Decision Making

Project Number: ED-01-PO-3664 (5-2)
Phone: 719/592-0347
Email: steve@assess.net.
<http://www.ablelinktech.com>.

The Self-Advocacy Movement: A History of the Unacknowledged Civil Rights Movement

Project Number: H133F020012
Phone: 612/625-6046
Email: hayde001@umn.edu.

Why do I see different grant numbers?

In 2014, President Obama signed the [Workforce Innovation and Opportunity Act \(WIOA\)](#) into law. As part of WIOA, the institute changed its name from the National Institute on Disability and Rehabilitation Research (NIDRR) to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and moved from the Department of Education to the Administration for Community Living (ACL) at the Department of Health and Human Services. Approximately 250 active grants received new ACL grant numbers and all new grants funded under NIDILRR have only an ACL grant number. For more information about NIDILRR/ACL grant numbers please visit: <http://naric.com/?q=en/content/about-nidilrracl-grant-numbers-0>.



Documents from NARIC's REHABDATA search listed are listed below:

2016

(2016). Critical issues in intellectual and developmental disabilities: Contemporary research, practice, and policy.

NARIC Accession Number: R09389

ABSTRACT: This book provides a concise review of what is known about ten key areas in the field of intellectual and developmental disabilities (IDD) and what that knowledge means for future developments in public policy, research, and practice. The review examines the following critical areas that touch the lives of people with IDD: (1) aging, retirement, and end of life; (2) education; (3) employment and economic self-sufficiency; (4) health and wellness; (5) justice; (6) long-term supports and services; (7) self-determination and self-advocacy; (8) social inclusion; (9) supports for families; and (10) workforce issues.

Ju, S., Roberts, E.L., & Zhang, D. (2016). **Review of practices that promote self-advocacy for students with disabilities.** *Journal of Disability Policy Studies*, 26(4), 209-220.

NARIC Accession Number: J73110

ABSTRACT: This literature review investigated self-advocacy practices for students with disabilities published in peer-reviewed journals from June 2004 to June 2012. As an update to the study done by Test, Fowler, Brewer, and Wood (2005), who reviewed self-advocacy intervention studies published from 1972 to June 2004, the authors reviewed 18 empirical studies published from June 2004 to June 2012. The reviewed practices taught self-advocacy skills through published curricula, peer tutoring, writing strategies, employment skills training, transition planning involvement, direct instruction, college-based transition programs, a weeklong program, and supporting students to lead their individualized education program meetings. Interpretations included a continued need to study program effects on students from diverse backgrounds and more rigorous research on self-advocacy predictors and outcomes. Compared with the previously reviewed studies, recent single-case studies improved participant selection reporting

and procedural fidelity but declined in controlling for internal validity; group experimental studies improved from the previously reviewed studies in measuring dependent variables at appropriate times and using appropriate analysis and declined in reporting intervention agent details. Two studies (one single-case and one group experimental) met quality indicator standards for "high quality," and no study met the "acceptable" standards.

2015

Abery, B., Antosh, A., Broussard, R., Coppens, B., Finn, C., Goodman, A., Harris, C., Knapp, J., Martinis, J., Ne'eman, A., Nelis, T., Shogern, K.A., & Wehmeyer, M.L. (2015). **Recommendations of the self-determination and self-advocacy strand from the national goals 2015 conference.** *Inclusion*, 3(4), 205-210.

NARIC Accession Number: J73052

Project Number: 90RT5039, H133B130006, H133B130007

ABSTRACT: Article reports the recommendations of the Self-Determination and Self-Advocacy Strand from the National Goals 2015 conference. The recommendations provide direction on research goals to advance policy and practice related to self-advocacy and self-determination over the next 10 years. Seven recommendations and multiple sub-recommendations were developed over a 2-day meeting by leaders in the field of intellectual and developmental disabilities. The recommended goals provide direction for research initiatives related to collective self-advocacy and personal self-determination. Implications for the field are discussed.

Butterworth, J., Heller, T., & Hewitt, A. (2015). **Introduction to the special issue: National goals 2015.** *Inclusion*, 3(4), 201-204.

NARIC Accession Number: J73051

Project Number: H133B130006, H133B130007, H133B140026

ABSTRACT: This article introduces a special journal issue devoted to the National Goals in Research, Practice, and Policy conference (also referred to as the National Goals 2015 conference). The purpose of this conference was to bring together stakeholders to summarize the current state of knowledge and identify

a platform of national research goals that will have the greatest impact on practice and policy concerning intellectual and developmental disabilities by 2025. The conference had 10 areas of focus: self-determination and self-advocacy; social inclusion; education; employment and economic self-sufficiency; long-term supports and services; health and wellness; aging, retirement, and end of life; supports for families across the life course; trends in the workforce; and justice. The participants in each strand participated in facilitated discussions on key questions that were used to assist the group in deliberating and in identifying and prioritizing new research goals. Each article included in this issue: (1) provides a relevant literature review and analysis, (2) describes the methods used to develop the goals, (3) identifies the goals and the rationale for the selected goals, and (4) addresses the implications.

Coppens, B., Nelis, T., & Shogren, K.A. (2015). *Issue brief: Self-determination and self-advocacy by people with IDD.*

NARIC Accession Number: O20109

Project Number: H133B130006, H133B130007, H133B140026

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=129651>.

ABSTRACT: This brief describes the research goals identified by participants at the National Goals Conference in Washington, DC in August 2015, who were charged with addressing self-determination and self-advocacy for people with intellectual and developmental disabilities (IDD). People with IDD have the capacity to make choices and express preferences, solve problems, engage in making decisions, set and attain goals, self-manage and self-regulate action, self-advocate, and acquire self-awareness and self-knowledge. Such actions, known as self-determination, emerge across the lifespan and the value of developing these skills is endorsed in public policies concerning education, health, employment, and community-living for people with IDD. However, research is necessary to assure that practices and interventions support optimal skill development and self-determination outcomes. The goals described provide a vision for leaders in the self-advocacy movement, researchers, funding agencies, policy-makers, and practitioners for key considerations that must be emphasized to facilitate the conditions that enable all people with IDD to lead self-determined lives.

Finn, C., Nelis, T. (2015). *Self-determination and self-advocacy for people with intellectual and developmental disabilities.*

NARIC Accession Number: O20577

Project Number: H133B130006, H133B130007, H133B140026

Video available at: <https://www.youtube.com/watch?v=HnmGgGjOhvY>.

ABSTRACT: This is part 4 of 18 in a series of videos from the National Goals in Research, Policy, and Practice meeting. The meeting aimed to advance a research agenda that influences policy and practice for and with people who have intellectual and developmental disabilities (I/DD) over the next ten years. Two individuals share their ideas on what self-advocacy and self-determination means to them and other individuals with I/DD. They talk about the self-advocacy movement, managed care and the medical system, peer-to-peer support, self-advocacy organizations, what they think needs to be done in the future to promote self-determination, and how important it is to teach these skills to individuals with a disability. Run time: 7 minutes 33 seconds.

Shogren, K. (2015). *Self-determination and self-advocacy for people with intellectual and developmental disabilities.*

NARIC Accession Number: O20576

Project Number: H133B130006, H133B130007, H133B140026

Video available at: <https://www.youtube.com/watch?v=h5-T1fFN5SA>.

ABSTRACT: This is part 3 of 18 in a series of videos from the National Goals in Research, Policy, and Practice meeting. The meeting aimed to advance a research agenda that influences policy and practice for and with people who have intellectual and developmental disabilities (I/DD) over the next ten years. Speaker defines what self-determination is and how to promote it, talks about the self-advocacy movement, and emphasizes how critically important self-determination is for individuals with I/DD to help them take an active part in making decisions and setting goals for what they want and need in life. In addition, she talks about three areas (creating opportunities, providing supports, and accommodations for self-determination) research is focused on and an evidence-based practice called the self-determined model of instruction. Run time: 10 minutes 04 seconds.

2014

McNaught, J., & Moore, M. (2014). **Virginia's self-determination project: Assisting students with disabilities to become college and career ready.** *Journal of Vocational Rehabilitation*, 40(3), 247-254. NARIC Accession Number: J68686

ABSTRACT: Article describes the Virginia Department of Education's I'm Determined project, a statewide initiative designed to help students with disabilities in middle and high school to learn and demonstrate the self-determination skills necessary to become college and career ready. Self-determination is a broad term referring to behavior that comes from a combination of several sub-skills, including decision-making, problem-solving, goal setting and attainment, self-advocacy, self-awareness, and self-regulation. The components of the I'm Determined project includes the self-determination skills of choice making, decision making, problem solving, goal setting, leadership, self-advocacy, and self-awareness. Information and strategies on how these skills are incorporated into the daily lives of students with disabilities as they prepare for adulthood are discussed. Outcomes of the project have shown increased confidence, self-acceptance, advocacy, and leadership skills in students with disabilities.

Ward, M., & Wehmeyer, M. (2014). **Self-determination: Past, present, future.**

NARIC Accession Number: O20086

Project Number: H133B130011

Video available at: <http://www.vcurrtc.org/training/webcastDetails.cfm/282>. Free registration is required to view webcast.

ABSTRACT: Speakers define and talk about what self-determination is and present a brief history of research findings and progress made over the last twenty-five years. They stress the importance of teaching individuals with disabilities how to acquire the skills and knowledge needed to become more self-determined, which leads to more success in the school setting, community inclusion, supported employment, vocational rehabilitation services, and related employment outcomes. In addition, they share ideas on future research and offer suggestions on how to increase self-determination, not only for individuals with a disability, but all youth. Run time: 54 minutes 27 seconds.

2013

Agran, M., Cosgriff, J.C., Hughes, C., & Washington, B.H. (2013). **Student self-determination: A preliminary investigation of the role of participation in inclusive settings.** *Education and Training in Autism and Developmental Disabilities (formerly Education and Training in Developmental Disabilities; Education and Training in Mental Retardation and Developmental Disabilities)*, 48(1), 3-17.

NARIC Accession Number: J65629

ABSTRACT: Study examined the association between students' inclusive school and community activities and the self-determination skills of active involvement in individualized education program (IEP) activities and use of selected self-determination strategies. Interviews were conducted with 47 students with severe intellectual disability from three high schools; one high school was undergoing state takeover for consistently failing to make annual yearly progress and served students living in a high-poverty community. Findings revealed significant differences across schools in student participation in general education and school- and community-based transition activities, which were associated with level of self-determination skill use. Students attending schools offering more inclusive activities reported significantly more use of six of nine self-determination skills: self-advocacy, choice making, self-reinforcing, self-monitoring, self-evaluating, and problem solving. Active student IEP participation was reported to be low across all schools. The implications of the findings for future research and practice are discussed.

Carter, E.W., Cooney, M., Lane, K.L., Machalicek, W., Moss, C.K., & Weir, K. (2013). **Parent assessments of self-determination importance and performance for students with autism or intellectual disability.** *American Journal on Intellectual and Developmental Disabilities (formerly American Journal on Mental Retardation AJMR)*, 118(1), 16-31.

NARIC Accession Number: J65561

ABSTRACT: Study assessed the self-determination of children and youth with intellectual disability and/or autism from the perspectives of their parents or caregivers. Six hundred twenty-seven parents/caregivers of children with intellectual disability or

autism attending one of 34 randomly selected school districts: (1) rated the importance of 7 component skills associated with self-determination, (2) assessed their children's performance in relation to those 7 skills, and (3) evaluated the overall self-determination capacities of their children. Although parents highly valued all of the self-determination skills, the degree to which their children were reported to perform the skills well was fairly low. Several factors predicted higher levels of self-determination, including educational setting, the presence of challenging behaviors, and perceived disability severity. The authors offer recommendations for equipping parents to better support their children's self-determination development.

Carter, E.W., Cooney, M., Lane, K.L., Machalicek, W., Moss, C.K., & Weir, K. (2013). **Self-determination among transition-age youth with autism or intellectual disability: Parent perspectives.** *Research and Practice for Persons with Severe Disabilities RPSD (formerly Journal of the Association for Persons with Severe Handicaps JASH)*, 38(3), 129-138.

NARIC Accession Number: J67832

ABSTRACT: Study examined 68 parents' views of the self-determination skills and capacities of their young adult children (ages 19 to 21 years) with autism spectrum disorders and intellectual disability. Results indicated that parents placed a high value on the importance of all seven component skills (choice-making skills, decision-making skills, goal-setting skills, problem-solving skills, self-advocacy and leadership skills, self-awareness and self-knowledge, and self-management and self-regulation skills) associated with enhanced self-determination. Yet, parents indicated that their young adult children did not often perform these skills well. Effect sizes suggested high-magnitude differences between parents' ratings of the importance and their child's performance for each self-determination skill evaluated. Furthermore, regression analyses indicated parents' perceptions of the severity of their child's disability accounted for a significant portion of the variance in the overall ratings of their child's performance of these seven skills and overall self-determination capacity. Parents who described their children's disabilities as being less severe rated their children as having higher perfor-

mance levels on both measures of self-determination. Implications for practice, study limitations, and recommendations for future research are discussed.

Factor, A.R., & Heller, T. (Eds.). (2013). **Research to practice in self-determination series: Issue 5: Self-determination and aging.** *National Gateway to Self-Determination, April.*

NARIC Accession Number: O19026

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=121992>.

ABSTRACT: The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. This issue focuses on aging. Topics include: the life stories of older self-advocates, using social media to support families, tools to advocate for better health care, personal thoughts on growing older, and sibling involvement in planning for the future.

Heller, T. (2013). **Self-determination and aging.** *National Gateway to Self-Determination: Research to Practice in Self-Determination Series. Issue 5: Self-Determination and Aging, 1-2.*

NARIC Accession Number: O19338

Project Number: H133B080009

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=123909>.

ABSTRACT: Article introduces this research-to-practice guide issue that focuses on challenges faced by adults with developmental disabilities as they age. An important element of aging well is living a self-determined life. However, many people with developmental disabilities have few opportunities for self-determination throughout their lives. Examples of strategies to promote self-determination include training and skill development, peer mentoring, provision of environmental supports, and changes in public policies.

2012

Arnold, K. (2012). *The sibling leadership network: Promoting self-determination through sibling advocacy. National Gateway to Self-Determination: Research to Practice in Self-Determination Series. Issue 4: Family Focus on Self-Determination, 21-22.*

NARIC Accession Number: O19336

Project Number: H133B080009

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=123907>.

ABSTRACT: Article presents a story that highlights the ways in which siblings can promote choice-making and opportunities for their brothers and sisters with disabilities. The article provides an overview of the Sibling Leadership Network, a national nonprofit organization dedicated to providing siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them.

Bates-Harris, C., Epstein, A., Goodman, S., Harles, C., Prokop, S., & Seifert, P. (2012). **Testimony of the Consortium for Citizens with Disabilities (CCD) employment and training task force.** *Journal of Vocational Rehabilitation, 36*(1), 21-31.

NARIC Accession Number: J63910

ABSTRACT: Article presents testimony from members of the Employment and Training Task Force of the Consortium for Citizens with Disabilities (CCD) regarding work incentive programs for Social Security beneficiaries. The CCD, which advocates on behalf of people with disabilities and chronic conditions and their families, is a smaller group within the coalition that addresses Federal disability employment issues, working to secure national public policy that advances self-determination, independence, empowerment, integration and inclusion in employment for individuals with disabilities. The Task Force supports improvements to Social Security disability work programs, critical avenues for social security beneficiaries to gain access to employment, to make it more effective in serving those who rely on it. This testimony was delivered to the United States House of Representatives, Ways and Means Committee, Subcommittees on Social Security and Human Resources.

Clark, D.M., Levitz, B., O'Hara, D., & Schwartz, A.A. (Eds.). (2012). *Research to practice in self-determination series: Issue 3: Self-determination and health. National Gateway to Self-Determination, September.*

NARIC Accession Number: O19024

ABSTRACT: The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. This issue focuses on health. Topics include: the role of self-determination in reducing health disparities, a self-advocate's view of health self-management, successful health promotion strategies, and clinical teaching resources for training health professionals.

Gotto, G., Heller, T., Palmer, S., Peterson-Besse, J., & Reynolds, S. (Eds.). (2012). *Research to practice in self-determination series: Issue 4: Family focus on self-determination. National Gateway to Self-Determination, October.*

NARIC Accession Number: O19025

ABSTRACT: The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. This issue focuses on the role of families to support self-determination. Topics include: the importance of families over time to support self-determination, siblings and self-determination, and how families can help with building social capital to enhance self-determination.

Lulow, E. (2012). *Youth voice in advocacy: A guide to strategic sharing.*

NARIC Accession Number: O19399

Project Number: H133B090019

Video available at: [http://www.pathwaysrtc.pdx.edu/webinars/Webinar Youth Voice in Advocacy 05 15 2012.wmv](http://www.pathwaysrtc.pdx.edu/webinars/Webinar_Youth_Voice_in_Advocacy_05_15_2012.wmv).

ABSTRACT: The presenter believes strategic sharing will help individuals develop their capabilities to share their stories and experiences and is one of the most important things young people need to prepare and be trained in before doing advocacy work. Along with defining what strategic sharing is, the topics discussed include: the history and importance

of strategic sharing; reasons, benefits, and risks of sharing; how to prepare for an advocacy event; tips on how to be strategic; and resources. Run time: 54 minutes 47 seconds.

Marks, B., & Sisirak, J. (2012). *Health matters for people with intellectual and developmental disabilities: Take charge!. National Gateway to Self-Determination: Research to Practice in Self-Determination Series. Issue 3: Self-Determination and Health, 5-6.*

NARIC Accession Number: O19335

Project Number: H133B080009

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=123906>.

ABSTRACT: Article introduces the HealthMatters community academic partnership (CAP), a collaboration which aims to enhance the health status and optimize the full community participation of people with intellectual and developmental disabilities (I/DD). Through HealthMatters, two community-based organizations and an academic institution are working together to find practical solutions using evidence-based curricula and training to improve health. Currently, the HealthMatters CAP is building the infrastructure to facilitate and sustain healthy choices and behaviors among people with I/DD through the following: workforce capacity development for health promotion in community sectors; health advocacy capacity building for people with I/DD; and active participation among people with I/DD in health promotion and health advocacy.

Shogren, K. (2012). **Hispanic mothers' perceptions of self-determination.** *Research and Practice for Persons with Severe Disabilities RPSD (formerly Journal of the Association for Persons with Severe Handicaps JASH)*, 37(3), 170-184.

NARIC Accession Number: J64908

ABSTRACT: Study explored the perceptions of self-determination and self-determined behavior held by seven mothers of transition-age youth with severe disabilities who were Hispanic. Each mother was actively engaged in advocacy related to diverse children with disabilities in their local schools and communities. The mothers were asked about the role that self-determined behavior played in their family, their perceptions of the influence of culture on self-determination, and how they perceived self-determined

behavior being operationalized in schools. Themes emerged from the interviews and were grouped into five categories: (1) defining self-determination, (2) creating opportunities for self-determination, (3) goals for the future, (4) cultural influences, and (5) school-family conflicts. Participants felt that self-determination was important for their children but described differences in the ways that they operationalized self-determined behavior in the home. These differences led to conflicts between activities at home and at school, and the mothers by-and-large felt their cultural values were disregarded or disrespected when working with professionals to set goals for the future. Implications for future research and practice are discussed.

2011

Arnold, K. (2011). *Self-determination and self-advocacy. National Gateway to Self-Determination, March, 3-5.*

NARIC Accession Number: O18415

Project Number: H133B080009

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=117828>.

ABSTRACT: The author describes her experience of planning for the future of her sister who has developmental disabilities. She says that it is through that experience that she has come to better understand the importance of self-determination and self-advocacy.

Bambara, L.M., & Nonnemacher, S.L. (2011). **"I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs.** *Intellectual and Developmental Disabilities - IDD (formerly Mental Retardation)*, 49(5), 327-340.

NARIC Accession Number: J62231

ABSTRACT: This qualitative interview study explored the perceptions of adults with intellectual disability regarding interpersonal or social supports needed to express their own self-determination. Specifically, 10 adults, all members of a self-advocacy group, were asked to discuss their understanding of the term self-determination and ways in which support staff have either supported or inhibited their self-determination. Ten themes characterizing supportive and impeding staff actions were identified. The need for greater exploration of environmental and social influences on self-determination is emphasized.

Beckmann, C., Calkins, C.F., Gotto, G.S., Hunley, S., Jackson, L.W., Peterson, J., & Peterson, M. (Eds.). (2011). *Research to practice in self-determination series: Issue 1: Self-determination and self-advocacy. National Gateway to Self-Determination, March.*

NARIC Accession Number: O18404

ABSTRACT: The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. This issue focuses on self-advocacy. Topics include: the link between self-determination and self-advocacy, sibling perspectives on self-advocacy, the steps to building social capital, and moving beyond tokenism.

Broussard, R., & Shogren, K.A. (2011). **Exploring the perceptions of self-determination of individuals with intellectual disability.** *Intellectual and Developmental Disabilities (formerly Mental Retardation)*, 49(2), 86-102.

NARIC Accession Number: J61049

ABSTRACT: Study explored the perceptions of self-determination for people with intellectual disability. Interviews were conducted with 17 individuals who had intellectual disability to examine the impact of self-determination in their lives. Themes emerging from the interviews were grouped into three categories: meaning of self-determination, learning about self-determination, and dreams for the future. Participants described self-determination as being able to make choices and be in control of one's life and setting, as well as being able to work toward goals and engage in advocacy. Participants discussed the importance of supports for expressing self-determination and identified environmental characteristics that promoted and inhibited self-determination. Overall, their perceptions confirm the importance of promoting personal development of skills and attitudes associated with self-determination and systems change to create environmental opportunities for self-determination and causal agency. Implications for future research and practice are discussed.

2010

Hoffman, J. (2010). *Conversations about advocacy: Making a difference for yourself, your community, and the world.*

NARIC Accession Number: O18473

Project Number: H133N060033

Video is available at: <http://sci.washington.edu/info/forums/reports/advocacy.asp>.

ABSTRACT: Forum includes four individuals with spinal cord injury who discuss the different ways they have had involvement with advocacy from personally advocating for themselves, to the transition out into the community, to talking about advocating for larger causes and improving the lives of others both locally and nationally. Each panelist provides their background information and experiences, and answers follow up questions. Run time: 64 minutes.

2009

Aue, N., Gowen, L.K., & Walker, J.S. (Eds.). (2009). *Focal point: Youth empowerment and participation in mental health care*, 23(2), 1-32.

NARIC Accession Number: O17559

Project Number: H133B040038

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=109715>.

ABSTRACT: This issue describes a number of effective interventions that promote youth involvement in shaping mental health services. Topics include: youth-led participatory action research for mental health justice with Youth In Focus; an action research project with Youth In Focus; digital storytelling; improving outcomes through interventions that increase youth empowerment and self-determination; reflections of a youth advisor on developing a new intervention; new measure of youth mental health empowerment; the Youth 'N Action program; youth voice and participation on the national youth summit advisory board; Youth Motivating Others through Voices of Experience (Youth MOVE) National, a youth-led advocacy organization, and peer mentoring.

2007

(2007). *Peer support: Developing and facilitating self-help groups. Community Integration Tools.*

NARIC Accession Number: O16809

Project Number: H133B031109

Available in full-text at: <http://search.naric.com/research/rehab/download.cfm?ID=109715>.

ABSTRACT: This fact sheet contains practical information about planning and facilitating a peer-led, self-help group. It includes: basic information on how to develop a good meeting, a sample agenda, and facilitation tools that use active listening and conflict resolution to maintain a good meeting.

2006

Jones, M. (2006). **Teaching self-determination: Empowered teachers, empowered students.**

Teaching Exceptional Children, 39(1), Pgs. 12-17.

NARIC Accession Number: J51389

ABSTRACT: Article offers guidelines for teaching self-determination and empowering students with disabilities in today's schools. Five basic steps are outline for empowering students to become self-advocates and leaders in their individualized education plan decision-making processes. They are: (1) encourage disability awareness and self-discovery, (2) teach students about special education services, (3) engage students in self-monitoring, (4) prepare for student participation, and (5) evaluate the effectiveness of your efforts.

Post, M., & Storey, K. (2006). **Self-determination and informed choice.** *TASH Connections (formerly TASH Newsletter)*, 32(5/6), 30-33.

NARIC Accession Number: J51165

ABSTRACT: Article examines the concept of informed choice and its relationship to the development of self-determination skills for people with disabilities. Three case examples illustrate some of the issues involved in making meaningful informed choices.

2005

(2005). *Individual control of funding. Beach Center Newsletter*, 4.

NARIC Accession Number: O16034

Project Number: H133B031133

ABSTRACT: Newsletter of the Beach Center on Disability. This issue focuses on individual control of budgets, supports, and services. Topics include: (1) person-centered planning, individual budgets, and brokerage; (2) Medicaid waivers and individual control; (3) self-determination for individuals with significant cognitive disabilities; (4) books review: The Support Broker's Manual; (5) Center for Self-Determination; (6) tips for consumers on how to implement control of funding; and (7) project news and resources.

2004

Cook, J.A., Jonikas, J.A., & Petersen, C. (2004). *Express yourself! Assessing self-determination in your life.*

NARIC Accession Number: O16085

Project Number: H133B000700

Available in full-text at: <http://www.cmhsrp.uic.edu/download/sd-self-assessment.pdf>.

ABSTRACT: Self-assessment checklist is designed to help individuals determine the level of self-determination and identify areas where improvements can be made. Areas covered in this self-assessment include finances, housing, transportation, employment, community integration, medical treatment, and mental health care. A list of useful Web sites is included.

Full-text copies of these documents may be available through NARIC's document delivery service.

To order any of the documents listed above, note the accession number and call an information specialist at 800/346-2742.

There is a charge of 5 cents for copying and shipping with a \$5 minimum on all orders.



Documents from the International Research Collection available through REHABDATA are listed below:

2012

Andrews, A., Barber, R., Feldman, M.A., Hamelin, J., & Owen, F. (2012). **Health self-advocacy training for persons with intellectual disabilities.** *Journal of Intellectual Disability Research*, 56(11), 1110-21.

NARIC Accession Number: I196011

Abstract is available at: <https://www.ncbi.nlm.nih.gov/pubmed/23106754>.

Aznar, A.S., González, Castañón, D., & Olate, G. (2012). **The ITINERIS scale on the rights of persons with intellectual disabilities: development, pilot studies and application at a country level in South America.** *Journal of Intellectual Disability Research*, 56(11), 1046-57.

NARIC Accession Number: I196016

Abstract is available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2012.01651.x/abstract>.

Boyle, F.M., Brolan, C.E., Dean, J.H., & Taylor, G.M. (2012). **Health advocacy: A vital step in attaining human rights for adults with intellectual disability.** *Journal of Intellectual Disability Research*, 56(11), 1087-1097.

NARIC Accession Number: I182549

Abstract is available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2012.01637.x/abstract>.

Jenkins, R. (2012). **Using advocacy to safeguard older people with learning disabilities.** *Nursing Older People*, 24(6), 31-6.

NARIC Accession Number: I201534

Abstract is available at: <https://www.ncbi.nlm.nih.gov/pubmed/22900394>.

2009

Björnsdóttir, K., & Jóhannesson, I.A. (2009). **People with intellectual disabilities in Iceland: A bourdieuean interpretation of self-advocacy.** *Intellectual and Developmental Disabilities*, 47(6), 436-46.

NARIC Accession Number: I113848

Abstract is available at: <https://www.ncbi.nlm.nih.gov/pubmed/20020799>.

2008

Llewellyn, P., Northway, R. (2008). **The views and experiences of people with intellectual disabilities concerning advocacy: A focus group study.** *Journal of Intellectual Disabilities*, 12(3), 213-28.

NARIC Accession Number: I93292

Abstract is available at: <https://www.ncbi.nlm.nih.gov/pubmed/18728143>.



Documents from the Education Resource Information Center (ERIC) search at www.eric.ed.gov are listed below:

2016

Allen, R.D., Cuenca-Carlino, Y., Gilbert, J., & Mustian, A.L. (2016). **I have a voice and can speak up for myself through writing!** *Intervention in School and Clinic*, 51(4), 220-228.

ERIC Number: EJ1089833

ABSTRACT: Writing can be a method of expression for those who cannot or do not feel comfortable expressing themselves verbally. For students with disabilities, however, writing can be a challenging task because they often fail to see writing as a process. This article examines how to use the self-regulated strategy development model of writing, an evidence-based practice, to teach middle and high school students with emotional/behavioral disabilities to use persuasive writing as a tool to advocate for their needs and wants. Writing can help students develop self-determination skills and self-expression with the time needed to reflect on what they want to say, making the process of writing an empowering one. Example lessons, guidelines, and sample materials are provided.

2015

Camilleri, K., Clarke, R., & Goding, L. (2015). **What's in it for me? The meaning of involvement in a self-advocacy group for six people with intellectual disabilities.** *Journal of Intellectual Disabilities*, 19(3), 230-250.

ERIC Number: EJ1124252

ABSTRACT: Background: This article explores the experiences of six people with intellectual disabilities in the context of a self-advocacy group, identifying the benefits and difficulties of being part of the group. Materials and Methods: Six adults with intellectual disabilities were interviewed about their experiences. Each individual took part in two individual and two group interviews. The transcripts were analysed using thematic analysis. Results: Analysis revealed four themes, namely, being part of the group, self-esteem, self-determination and empowerment. Conclusion: Being part of the group is central to the experience of self-esteem, self-development and empowerment. Re-

sponses allow the exploration of the interrelationship between individual, group and community. Consideration is given to models of disability and the evidence base in relation to personal and political outcomes of self-advocacy. Links are made with developing a sense of self, self-determination, interpersonal learning and building resilience. Implications for practice are discussed.

Daly-Cano, M., Newman, B., & Vaccaro, A. (2015). **College student narratives about learning and using self-advocacy skills.** *Journal of Postsecondary Education and Disability*, 28(2), 213-227.

ERIC Number: EJ1074673

Available in full-text (PDF) at: <http://files.eric.ed.gov/fulltext/EJ1074673.pdf>.

ABSTRACT: Self-advocacy is the ability to communicate one's needs and wants and to make decisions about the supports needed to achieve them (Stodden, Conway, & Chang, 2003). Research shows self-advocacy skills are related to academic performance and successful adaptation to college (Adams & Proctor, 2010; Getzel & Thoma, 2008; Hadley, 2006; Murray, Lombardi, & Kosty, 2014; Thoma & Wehmeyer, 2005). Yet, few studies have documented how youth learn to self-advocate and even fewer have delved deeply into how or when students use self-advocacy skills in college. Narratives gleaned from eight students with disabilities in a qualitative grounded theory study begin to fill this gap. Participants reported learning self-advocacy skills from family members and educators early in life. Findings from this study also demonstrate that college students utilized self-advocacy skills in three different ways: proactively, reactively, and retrospectively. Recommendations to enhance the self-advocacy skills of students with disabilities are provided for family members, K-12 personnel, and postsecondary educators.

Griffiths, S., & Ryan, T.G. (2015). **Self-advocacy and its impacts for adults with developmental disabilities.** *Australian Journal of Adult Learning*, 55(1), 31.

ERIC Number: EJ1059141

Available in full-text (PDF) at: <http://files.eric.ed.gov/fulltext/EJ1059141.pdf>.

ABSTRACT: The following review of literature illuminates self-advocacy from a North American transformational learning perspective via meaningful impacts, which arise for adults with developmental

disabilities, as well as various communities and their members. For adults with developmental disabilities, increased leadership capabilities and the evolution of new self-concepts continue to be powerful examples of the impact of self-advocacy. For communities, a more prominent voice and personable research within the academic community, increased awareness for some boards and committee members, and the acknowledgement and support of local or online community members are broad examples of the impacts self-advocacy has on us.

2014

Anderson, D., Gibb, G.S., Prater, M.A., & Redman, A.S. (2014). **Teaching adolescent students with learning disabilities to self-advocate for accommodations.** *Intervention in School and Clinic, 49*(5), 298-305.

ERIC Number: EJ1022727

ABSTRACT: In the general education classroom students with learning disabilities (LD) often need academic accommodations to be successful. These accommodations are typically selected and implemented by their general education teachers, not by the students themselves. High school students with LD were taught to recognize when an accommodation was needed, select the appropriate accommodation, request the accommodation, and then implement the accommodation in the general education classroom. To evaluate the effectiveness of the instruction, four students were observed in the general classroom.

2008

Marks, S.U., & Schaffer, J. (2008). **Promoting self-determination through a movie project.** *TEACHING Exceptional Children Plus, 4*(6), Article 5.

ERIC Number: EJ967726

Available in full-text (PDF) at: <http://files.eric.ed.gov/fulltext/EJ967726.pdf>.

ABSTRACT: The concepts of self-determination and self-advocacy have been a focus in the education of students with disabilities and many new curricula, guidelines, and materials have recently become available for educators. This article describes a project that involved individuals with intellectual disabilities in making a movie as a strategy for exploring and de-

veloping self-advocacy skills. A facilitator/director worked with the individuals as they discussed movie ideas based on self-determination, while learning concepts and working on component skills such as self-advocacy and problem solving. The authors share what they learned during the project and provide ideas for educators to follow a similar model with their students. (Contains 4 figures and 1 table.)

2007

Danneker, J.E., & Fiedler, C.R. (2007). **Self-advocacy instruction: Bridging the research-to-practice gap.** *Focus on Exceptional Children, 39*(8), 1.

ERIC Number: EJ788789

ABSTRACT: Special education literature abounds with a challenge to special educators to promote the acquisition of self-determination skills in their students. A critical component of self-determination that can be readily addressed in the school setting is self-advocacy. The authors believe that meeting the challenge of enhancing student's self-advocacy skills will require that educators understand self-advocacy and recognize its significance in obtaining successful outcomes for students with disabilities once they leave the P-12 school system. To support teachers' understanding of why and how to make changes in special education practices, the authors begin with a brief discussion of self-determination theory, which points to the important role of self-determination in learning and provides context for understanding the concept of self-advocacy. In addition, they provide definitions of self-determination and a conceptual framework for self-advocacy--the focal point of this article. The authors outline the need for explicit instruction related to component skills of self-advocacy and describe the barriers to providing this type of instruction in preschool to grade 12 (P-12) schools. Next, they explore the research-to-practice gap and offer descriptions of curricula and strategies for integrating self-advocacy skills into daily activities that they hope will bridge that gap. Finally, they illustrate connections between theory and practice by describing the experiences of four elementary students, their parents, and their teachers as these students practiced self-advocacy by leading their own Individualized Education Program (IEP) meetings. (Contains 3 figures.)

McCarthy, D. (2007). **Teaching self-advocacy to students with disabilities.** *About Campus*, 12(5), 10-16.

ERIC Number: EJ791414

ABSTRACT: Prior to entering college, most students with disabilities are taught to rely on parents, teachers, doctors, and others to arrange for educational accommodations. In college, the job is theirs. As such, it is imperative that they learn self-advocacy prior to entering college. In this article, the author discusses how disability educators can help students with disabilities manage the difficult transition to college by teaching them self-advocacy. (Contains 6 notes.)



Documents from the National Library of Medicine PubMed search at www.pubmed.com are listed below:

2017

Anderson, S., & Bigby, C. (2017). **Self-advocacy as a means to positive identities for people with intellectual disability: 'We just help them, be them really'.** *Journal of Applied Research in Intellectual Disabilities*, 30(1), 109-120.

PMID: 26514344

ABSTRACT: BACKGROUND: Stigma attached to having an intellectual disability has negative implications for the social identities and inclusion of people with intellectual disability. AIM: The study explored the effects of membership of independent self-advocacy groups on the social identity of people with intellectual disability. METHOD: Using a constructivist grounded theory methodology, semi-structured interviews were conducted with 25 members of six self-advocacy groups which varied in size, resources, location and policy context: two based in the Australian states of Victoria and Tasmania and four in the UK. RESULTS: Collegiality, ownership and control by members characterized groups. They gave members opportunities for paid or voluntary work, skill development and friendship which contributed to their confidence and engagement with life. Possibilities for new more positive identities such as being an expert, a business-like person, a self-advocate and an independent person were opened-up. Self-advocacy is an important means of furthering social inclusion of people with intellectual disability.

2016

Hawley, L.A. (2016). **Self-advocacy for independent life: A program for personal self advocacy after Brain injury.** *Journal of Social Work in Disability & Rehabilitation*, 11, 1-12.

PMID: 27645683

ABSTRACT: Traumatic brain injury (TBI) can result in long-term injury-related disabilities. Individuals with TBI and their families must often advocate for themselves to secure resources to address their postinjury needs. However, the ability to advocate

may be compromised by the effects of the injury. The Self-Advocacy for Independent Life (SAIL) program aims to empower individuals and families with the skills of self-advocacy so they can navigate life after brain injury in a self-efficacious manner.

Nedlund, A.C., & Taghizadeh, L. (2016). **To protect and to support: How citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden.** *Dementia, 15*(3), 343-57

PMID: 27170586

ABSTRACT: Since living with dementia implies increasing difficulties in taking charge of rights due to cognitive as well as communicative impairments, many people with dementia are vulnerable and in need of support in order to realize full citizenship. In Sweden, all adults right to self-determination is strongly emphasized in law, regulations, and policies. Further, and in contrast to the situation in many other countries, people living with dementia cannot be declared as incompetent of making decisions concerning social care and their right to self-determination cannot legally be taken away. The article shows that in the Swedish welfare system, the focus is more on protecting the self-determination of citizens than on supporting people in making decisions and exercising citizenship. Subsequently, this causes legally constructed zones of inclusion and exclusion. This article examines and problematizes how different institutional contexts, legal constructions, norms, and practices in Sweden affect the management of issues concerning guardianship, supported decision-making and self-determination, and outline the implications for people living with dementia.

Reindl, M.S., Schippers, A., & Waltz, M. (2016). **Personalization, self-advocacy, and inclusion: An evaluation of parent-initiated supported living schemes for people with intellectual and developmental disabilities in the Netherlands.** *Journal of Intellectual Disabilities, 20*(2), 121-36.

PMID: 26864287

ABSTRACT: This study focused on parent-initiated supported living schemes in the South of the Netherlands and the ability of these living schemes to enhance participation, choice, autonomy and self-advocacy for people with intellectual or develop-

mental disabilities through personalized planning, support and care. Based on in-depth interviews with tenants, parents and caregivers, findings included that parent-initiated supported housing schemes made steps towards stimulating self-advocacy and autonomy for tenants. However, overprotective and paternalistic attitudes expressed by a significant number of parents, as well as structural constraints affecting the living schemes, created obstacles to tenants' personal development. The study calls for consideration of interdependence as a model for the relationship of parents and adult offspring with disabilities. The benefits and tensions inherent within this relationship must be taken into consideration during inclusive community building.

2015

Svensson, O., & Tideman, M. (2015). **Young people with intellectual disability—the role of self-advocacy in a transformed Swedish welfare system.** *International Journal of Qualitative Studies on Health and Well-being, 10*, 25100.

PMID: 25819844

Available in full-text (PDF) at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4377324/pdf/QHW-10-25100.pdf>.

ABSTRACT: A growing number of young people in Sweden with intellectual disability have organized themselves during the last 15 years in self-advocacy groups for socializing, empowerment, and expressing opposition to the norms and attitudes in a society that labels them as disabled. At the same time, the Swedish welfare system has transformed dramatically with processes of far-reaching individualization, closure of the major institutions, decentralization of responsibility from the state to local governments, and an emerging welfare market where service users are turned into customers. The aim of this article is to analyse and discuss the significance of self-advocacy in the new welfare context. Data were collected over a period of more than 10 years using repeated interviews with members of two self-advocacy groups and participation observations. Findings suggest that participation in self-advocacy groups opens up members for increasing health and well-being through new roles and identities, and it strengthens their control over everyday life. Support is still needed, however,

but in new ways; otherwise, the restrictions of the institutions will simply be reconstructed in the new welfare system.

2014

Blumenthal, J.A., & Kohn, N.A. (2014). **A critical assessment of supported decision-making for persons aging with intellectual disabilities.** *Disability and Health Journal*, 7(1 Suppl), S40-3.

PMID: 24456684

ABSTRACT: Supported decision-making is increasingly being promoted as an alternative to guardianship for persons aging with intellectual disabilities. Proponents argue that supported decision-making, unlike guardianship, empowers persons with disabilities by providing them with help in making their own decisions, rather than simply providing someone else to make decisions for them. To evaluate the empirical support for these claims, we reviewed the evidence base on supported decision-making. Our review found little such empirical research, suggesting that significant further research is warranted to determine whether—and under what conditions—supported decision-making can benefit persons with intellectual disabilities. Indeed, without more empirical evidence as to how supported decision-making functions in practice, it is too early to rule out the possibility it may disempower individuals with disabilities by facilitating undue influence by their alleged supporters. We therefore suggest several key areas for future research.

Central England People First History Project Team, & Walmsley, J. (2014). **Telling the history of self-advocacy: A challenge for inclusive research.** *Journal of Applied Research in Intellectual Disabilities*, 27(1), 34-43.

PMID: 24376079

ABSTRACT: **BACKGROUND:** This paper tells the story of Central England People First's (CEPF) History Project. **METHOD:** This was an inclusive research project, owned and controlled by members of CEPF which sought to chart its 21-year history, 1990-2012. **RESULTS:** It illustrates both the strengths of such a project and some of the challenges. **CONCLUSION:** It concludes that using inclusive research methods enabled the story to be told, but that it was less successful in addressing questions about why

the organization grew and prospered in the 1990s, only to struggle in its later years, and what this tells us about the conditions which enable self-advocacy to flourish. The paper was collaboratively written by the CEPF History Project team and an academic ally. Different fonts differentiate the contributions, although it is acknowledged that lots of the ideas were shared. This paper explores issues in telling the history of self-advocacy using inclusive research methods. It explains how and why CEPF recorded its history, what we found out, and some of the questions we have had to think about: whose voices we hear what to include, what to leave out what parts of the research people with learning difficulties can do what self-advocacy means to different people how to make use of research other people have done. It raises some new questions about directions for inclusive research. The Paper was written by the CEPF History team - Craig Hart, Ian Davies, Angela Still and Catherine O'Byrne - working with Jan Walmsley. We wanted to make it clear what were Jan Walmsley's ideas and what were our ideas. We have done this by writing our ideas in a different font. BUT lots of the ideas belong to all of us.

Mitchell, F. (2014). **Facilitators and barriers to informed choice in self-directed support for young people with disability in transition.** *Health & Social Care in the Community*, 23(2), 190-9.

PMID: 25233846

ABSTRACT: The objective of this qualitative study was to explore the concept of 'informed choice' in the context of self-directed support (SDS) for young people with disability in transition from child to adult services. SDS is a major policy initiative introduced by the Scottish government to promote personalized services by redefining the relationship between the citizen and the state regarding social care supports. Informed choice is one of the underpinning principles of the Social Care (Self-directed Support) (Scotland) Act 2013. The theoretical approach to the research study was that of critical realism; specifically, realistic evaluation. The research design used multiple qualitative methods involving secondary analysis of archived qualitative longitudinal interview data, and primary interviews with nine individuals, representing a wide range of stakeholders in Scotland. The study developed hypotheses concerning the facilitators and

barriers to informed choice for young people with disability. Factors facilitating informed choice included supportive family and professional networks, advocacy, accessible information and experiential knowledge. Barriers to informed choice were seen to be low expectations, poor collaboration between child and adult services and bureaucratic organizational cultures. SDS is entering the implementation phase of the policy cycle in Scotland and this study will inform emerging policy, practice and future research into personalization for young people with disability in transition. The findings point to the need to involve young people with disability at an early stage in choice-making, and to foster self-advocacy skills and supportive social networks. Informed choice for young people with disability needs to be seen as a process over time involving both information and emotions and both need to be supported to ensure successful transitions.

2013

Abery, B.H., & Wehmeyer, M.L. (2013). **Self-determination and choice.** *Intellectual and Developmental Disabilities, 51*(5), 399-411.

PMID: 24303826

ABSTRACT: Promoting self-determination and choice opportunities for people with intellectual and developmental disabilities has become best practice in the field. This article reviews the research and development activities conducted by the authors over the past several decades and provides a synthesis of the knowledge in the field pertaining to efforts to promote self-determination and choice.

Luckner, J.L., & Sebald, A.M. (2013). **Promoting self-determination of students who are Deaf or hard of hearing.** *American Annals of the Deaf, 158*(3), 377-86.

PMID: 24133961

ABSTRACT: Self-determination is a combination of attitudes, knowledge, and skills that enables individuals to make choices and engage in goal-directed, self-regulated behavior. Research in special education has demonstrated the benefits of promoting self-determination in achieving positive adult outcomes. However, to date, very little has been written about self-determination as it relates to the education

of students who are Deaf or hard of hearing. This article provides an overview of self-determination, suggestions for instructional planning, and guidance on resources that can be used to gather additional information.

2011

Caldwell, J. (2011). **Disability identity of leaders in the self-advocacy movement.** *Intellectual and Developmental Disabilities, 49*(5), 315-26.

PMID: 21905825

ABSTRACT: Life stories and perspectives of leaders in the self-advocacy movement were explored to enhance knowledge about disability identity formation. In-depth qualitative interviews were conducted with 13 leaders in the self-advocacy movement. Five major themes emerged: (a) resistance--claiming personhood and voice; (b) connection with disability community; (c) reclaiming disability and personal transformation; (d) interconnection with broader disability rights movement; and (e) bond with social justice and interdependency.

2007

Ferrari, L., Nota, L., Soresi, S., & Wehmeyer, M. (2007). **Self-determination, social abilities, and the quality of life of people with intellectual disability.** *Journal of Intellectual Disability Research, 51*(Pt 11), 850-65.

PMID: 17910537

ABSTRACT: BACKGROUND: The international literature has documented that self-determination is impacted by environmental factors, including living or work settings; and by intraindividual factors, including intelligence level, age, gender, social skills and adaptive behaviour. In addition, self-determination has been correlated with improved quality of life (QoL). This study sought to contribute to the growing literature base in this area by examining the relationship among and between personal characteristics, self-determination, social abilities and the environmental living situations of people with intellectual disabilities (ID). METHODS: The study involved 141 people with ID residing in Italy. Healthcare professionals and social workers who had known participants for at least one year completed measures of self-determination,

QoL and social skills. Analysis of variance was conducted to verify whether different levels of intellectual impairment were associated with different degrees of the dependent variables. The Pearson product-moment correlation was used to examine any relationships among dependent variables and IQ scores. Finally, discriminant function analysis was used to examine the degree to which IQ score, age, self-determination and social abilities predicted membership in groups that were formed based on living arrangement, and on QoL status (high vs. low). **RESULTS:** The anova determined, as expected, that participants with more severe ID showed the lowest levels of self-determination, QoL and social abilities. Discriminant function analysis showed that (a) individuals attending day centres were distinguished from those living in institutions in that they were younger and showed greater autonomy of choice and self-determination in their daily activities; (b) basic social skills and IQ score predicted membership in the high or low QoL groups; and (c) the IQ score predicted membership in the high or low self-determination groups. A manova conducted to examine gender- and age-level differences on self-determination found gender differences; women had higher self-determination scores than men. **CONCLUSIONS:** These findings contribute to an emerging knowledge base pertaining to the role of intraindividual and environmental factors in self-determination and QoL. In general, the study replicated findings pertaining to the relative contribution of intelligence to self-determination and QoL, added information about the potential contribution of social abilities, and pointed to the potentially important role of opportunities to make choices as a particularly important aspect of becoming more self-determined, at least in the context of residential settings.

2005

Goodley, D. (2005). **Empowerment, self-advocacy, and resilience.** *Journal of Intellectual Disabilities*, 9(4), 333-43.

PMID: 16330487

ABSTRACT: This article critiques the relationship between the aims of 'learning disability' policy and the realities of the self-advocacy movement. A previous study found that self-advocacy can be defined as the public recognition of the resilience of people with

learning difficulties. In the current climate of Valuing People, partnership boards and 'user empowerment', understanding resilience is crucial to the support of authentic forms of self-advocacy. This article aims to address such a challenge. First, understandings of resilience in relation to self-empowerment and self-advocacy are briefly considered. Second, the current policy climate and service provision rhetoric are critically explored. Third, it is argued that we need to recognize how self-advocacy groups celebrate resilience through a variety of social and identity-shifting actions. How current policy responds to these aspects of resilience is questioned. It is concluded that the lived reality of self-advocacy needs to be foregrounded in any attempt to understand empowerment.



Quick Looks

Online Resources Related to Advocacy, Self-Advocacy, & Self-Determination

Individuals with disabilities have the right to full-power all areas of their lives including the freedom to dictate control over how they live, learn, and work; participate in community activities and politics; and socialize. Self-determination focuses on choice-making, decision-making, problem-solving, goal-setting, and self-management. Self-advocacy is applying those choices, decisions, and goals to speaking up for one's self, negotiating for oneself, and communicating one's needs through various mediums (i.e., written word, and pictures or gestures). The following are a selection of resources related to self-determination, self-advocacy, empowerment, and more:

Access to Success: Free Online Training for College Students with Disabilities

This self-paced course teaches students with disabilities to advocate for accommodations on their behalf.

<http://www.accesstosuccess.ku.edu>

Autistic Self-Advocacy Network

The resource library includes policy advocacy toolkits related to health care, civic engagement, and home and community-based services.

Resource Library: <http://autisticadvocacy.org/resources>.

Curriculum for Self-Advocates: http://autisticadvocacy.org/wp-content/uploads/2015/02/CurriculumForSelfAdvocates_r7.pdf.

Getting and Advocating for Community-Based Housing: <http://autisticadvocacy.org/wp-content/uploads/2016/12/FND-community-based-housing-non-FL.pdf>.

Center for Parent Information and Resources

Contact: <http://www.parentcenterhub.org/about-us/#contact>.

Best-Practices in Self-Advocacy Skill Building (includes resources for youth, fact sheets, toolkits, etc.): <http://www.parentcenterhub.org/repository/priority-selfadvocacy>.

<http://www.parentcenterhub.org>.

Kansas University Beach Center on Disability

Phone: 785/864-7600

Email: beachcenter@ku.edu.

Self-Determination: <http://beach.drupal.ku.edu/self-determination>.

<http://beach.drupal.ku.edu>.

National Gateway to Self-Determination

Phone: 816/235-1755

Email: <http://www.ngsd.org/everyone/contact-us>.

Self-Advocacy for People with Disabilities:

<http://ngsd.org/audience-topic/for-people-with-disabilities/self-advocacy>.

Research to Practice in Self-Determination Series:

<http://www.ngsd.org/everyone/research-practice-self-determination-issues>.

<http://www.ngsd.org>.

National Research and Training Center on Psychiatric Disability (NRTC)

Phone: 312/355-1696

Resources/Tools related to self-determination for people with psychiatric disabilities:

<http://www.cmhsrp.uic.edu/nrtc/tools.asp>.

<http://www.cmhsrp.uic.edu/nrtc>.

National Resource Center for Supported Decision-Making

Phone: 202/448-1448

Email: JHJP@dcqualitytrust.org.

Resource Library: <http://supporteddecisionmaking.org/content/resource-library>.

<http://supporteddecisionmaking.org>.

PACER's National Parent Center on Transition and Employment

Toll Free: 888/248-0822

Email: transition@pacer.org.

Self-Determination: <http://www.pacer.org/transition/learning-center/independent-community-living/self-determination.asp>.

Explore the PACER Publication Catalog:

<http://www.pacer.org/publications>.

The following hand-outs may be of interest:

- ***Be Your Own Best Advocate***
<http://www.pacer.org/parent/php/PHP-c116.pdf>.
- ***How You Can Help Your Child Learn to be a Good Self-Advocate***
<http://www.pacer.org/parent/php/PHP-c95.pdf>.

Self-Advocacy Module through the [Heath Resource Center at the National Youth Transitions Center](#)

<https://www.heath.gwu.edu/self-advocacy>.

Self-Advocacy Online

Funded by the NIDILRR-funded RRTC on Community Living at the University of Minnesota, the Administration on Intellectual and Developmental Disabilities (AIDD), and other Federal agencies. The website offers resources in locating groups, learning about, and research on self-advocacy.

<http://www.selfadvocacyonline.org>.

Teaching Self-Advocacy Skills to Students Series

<https://teachingselfadvocacy.wordpress.com/description-of-self-advocacy>.

WrightsLaw.com

What is self-advocacy and various articles and resources on self-advocacy.

<http://www.wrightslaw.com/info/self.advocacy.htm>.

Search Terms for Advocacy, Self-Advocacy, & Self-Determination

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| <ul style="list-style-type: none"> 📖 Accessibility 📖 Academic Accommodations (Disabilities) 📖 Activities of Daily Living 📖 Adaptation 📖 Adolescents 📖 Adults 📖 Advocacy 📖 Aging 📖 Attitudes 📖 Augmentative and Alternative Communication (AAC) 📖 Autism 📖 Behavior Issues 📖 Brain Injury 📖 Capacity Building 📖 Caregiver(s) 📖 Children 📖 Citizenship 📖 College Preparation/Students 📖 Communication Skills 📖 Community 📖 Competence 📖 Deaf 📖 Decision-Making 📖 Dementia 📖 Developmental Disabilities 📖 Disabilities 📖 Disability Rights 📖 Education/Elementary/Secondary/Post-Secondary 📖 Educational Legislation 📖 Emotional Issues 📖 Employment 📖 Empowerment 📖 Equality 📖 Evidence-Based Practice 📖 Family 📖 Family-Centered Care 📖 Federal Legislation 📖 Foreign Countries 📖 Goal Setting 📖 Grounded Theory 📖 Group Homes 📖 Guardianship | <ul style="list-style-type: none"> 📖 Hard-of-Hearing 📖 Health 📖 Inclusion 📖 Independent Living 📖 Individuality 📖 Individualized Education Programs (IEPs) 📖 Informed Choice 📖 Institutionalization 📖 Integration 📖 Intellectual Disabilities 📖 Leadership Training 📖 Learning Disabilities 📖 Legislation 📖 Literature Reviews 📖 Medical Issues 📖 Netherlands 📖 Observation 📖 Outcomes 📖 Parent-Child Relationships 📖 Parents 📖 Participation 📖 Patient Advocacy 📖 Peer Groups/Supports 📖 People with Disabilities 📖 Personal Autonomy/Empowerment/Narratives 📖 Prejudice 📖 Problem Solving 📖 Program Effectiveness 📖 Psychiatric Disabilities 📖 Public Policy 📖 Qualitative Research 📖 Quality of Life 📖 Rehabilitation 📖 Research 📖 Self-Actualization 📖 Self-Advocacy 📖 Self-Concept 📖 Self-Determination 📖 Self-Directed Supports 📖 Self-Esteem 📖 Self-Help 📖 Service Delivery 📖 Skill Development |
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***Search Terms for Advocacy, Self-Advocacy, & Self-Determination
continued....***

- 📖 Social Behavior/Environment/Identification/
Influences/Supports
- 📖 Social Support Groups
- 📖 Social Work
- 📖 Special Education
- 📖 Special Needs Students
- 📖 Student Participation
- 📖 Supported Decision-Making
- 📖 Sweden
- 📖 Tasmania
- 📖 Teacher Role
- 📖 Teaching Methods
- 📖 Training
- 📖 Transformative Learning
- 📖 Transition
- 📖 United Kingdom
- 📖 Video Technology
- 📖 Welfare System
- 📖 Writing Skills/Strategies
- 📖 Young Adults
- 📖 Youth

About reSearch:

reSearch is an information product from the National Rehabilitation Information Center (NARIC). Each issue is based on real-world queries received by our information specialists from researchers, educators, and rehabilitation professionals around the world.

We search several sources both in-house and online, to fill these requests including:

 REHABDATA and the NIDILRR Program database

 Education Resources Information Center

 National Clearinghouse of Rehabilitation Training Materials

 Campbell and Cochrane Collaborations

 PubMed and other National Library of Medicine databases

 Agency for Health Care Policy and Research databases

 and other reputable, scholarly information resources.

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