#### Physical Activity, Sport & Disability: Research & Personal Experiences

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#### The "WHY": Who am I?

#### My Identities



#### Representation Matters

Image description: Young Anjali black and white photo in an older style "V" shaped racing wheelchair on a track with grass in the background. She is wearing a helmet with hand visible wearing a glove pushing on the rim and focused on the end of the race.





Image description: Children's drawing of person in pink racing wheelchair wearing yellow helmet at finish line of Boston Marathon. Speech bubbles from side say "Go Anjali Go" and Drawings of video cameras capturing the moment.

#### Sports Stage



Image description: (Left) Anjali sitting in day chair on podium with gold medal with green ribbon around neck and holding a plant in a basket with a big smile. In the background signs for the IPC Athletics World Championships and Christchurch and other sponsors can be seen.

Image description: (Right) Finish line photo finish of Anjali on a track in her red racing wheelchair wearing USA jersey and red sunglasses with one arm raised in air celebrating and one hand still on push rim with black gloves on.



## Common Concerns in Disability Sport

#### **Environmental Concerns**

- Transportation
- Cost
- Access to Specialized Equipment
- Accessibility of venues

#### **Individual Concerns**

- Autonomic dysreflexia (primarily issue for quadriplegics)
- Regulating body temperature
- Pressure sore / skin breakdown

# Community Programs & Coaches – Equipment Considerations

- Equipment is sport specific
- Equipment is customized to athlete's level of disability/ability
- Equipment can be program equipment or personal equipment
- Variety of manufacturers at a variety of price ranges
- Consult with a physical therapist if there is a concern
- Importance of partnerships in the community

#### **NIDILRR's Mission**

To generate new knowledge and to promote its effective use:



To improve the abilities of individuals with disabilities to perform activities of their choice in the community



To expand <u>society</u>'s capacity to provide full opportunities and accommodations for its citizens with disabilities

### About the Administraton for Community Living

The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.

By funding services and supports provided by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions.

# What We Sponsor (Annual Budget of \$118M)

Research & Development

 Knowledge, interventions and products to improve long-term outcomes and community living

Capacity Building  Training young investigators and retraining clinicians to pursue research careers

Knowledge Translation  Promoting the use of R&D findings by people with disabilities, their families, and other stakeholders

#### **Breadth of Responsibility**

 Children Populations across Transition age the lifespan Adults Aging All disability types Physical, sensory, **Cross-disability** ID/DD, Psychiatric Health and Function **Broad Outcome**  Employment Domains Community Living & **Participation** 

#### **Outcome Domains**



Health and Function



**Employment** 

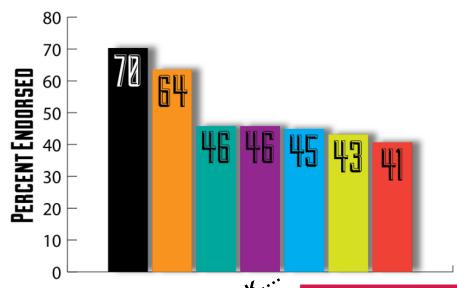


Community
Living and
Participation

# BARRIERS TO EXERGISES FOR PEOPLE WITH DISABILITES

- EXERCISE PROGRAM COST
- TRANSPORTATION TO FITNESS CENTER
- HOW TO EXERCISE
- WHERE TO EXERCISE
- FITNESS CENTER AVAILABILITY
- LACK OF ENERGY
- LACK OF MOTIVATION

THE HIGH INCIDENCE OF SECONDARY CONDITIONS REPORTED AMONG PEOPLE WITH DISABILITIES INCLUDING OBESITY, FATIGUE, PAIN, DECONDITIONING AND DEPRESSION, COMBINED WITH ENVIRONMENTAL BARRIERS THAT DISCOURAGE PARTICIPATION IN COMMUNITY EXERCISE PROGRAMS PRESENTS AN OPPORTUNITY FOR HEALTH PROFESSIONALS TO TARGET PEOPLE WITH DISABILITIES IN THEIR LONG RANGE PLANS.



In the U.K....

Barriers to sport and exercise

44555

**41%** of disabled adults say a lack of suitable activities stops them taking part



- Disability sport is beneficial to the health, psychosocial well-being, and identity of people with disabilities (Anderson, 2009; Mascarinas & Blauwet, 2018; NCHPAD, 2009)
- Physical inactivity is particularly prevalent among adults with disability (NCHPAD, 2009)
- Data from *Healthy People 2010* suggests that 56% of adults with a disability reported no leisure-time physical activity, compared to 36.2% of people without a disability. (Inclusive Fitness Coalition, 2015)
- Youth with disabilities are twice as likely to be physically inactive, resulting in obesity rates almost 40% higher than in youth without disabilities creating much higher risks for healthy-related diseases (CDC, 2017).

- Numerous physical health benefits from longtime NIDILRR grantee Dr.
   Rimmer (1999, 2008, 2014, 2012)
  - Lack of exercise is a serious public health concern for all people, but people with disabilities are at much greater risk of the serious health problems associated with physical inactivity.<sup>3</sup>
  - In the USA, adults with disability were twice as likely to be physically inactive than were those with no disability.<sup>4</sup>
  - Increased rates of physical inactivity were also reported in adults with disabilities from Canada (Martin Ginis et al, 2007) and Norway (Norvedt et al., 2005) and in children with disabilities in Hong Kong (Sit et al, 2007)

People with disabilities who are involved in adaptive sports and recreation in the community are **more** likely to:

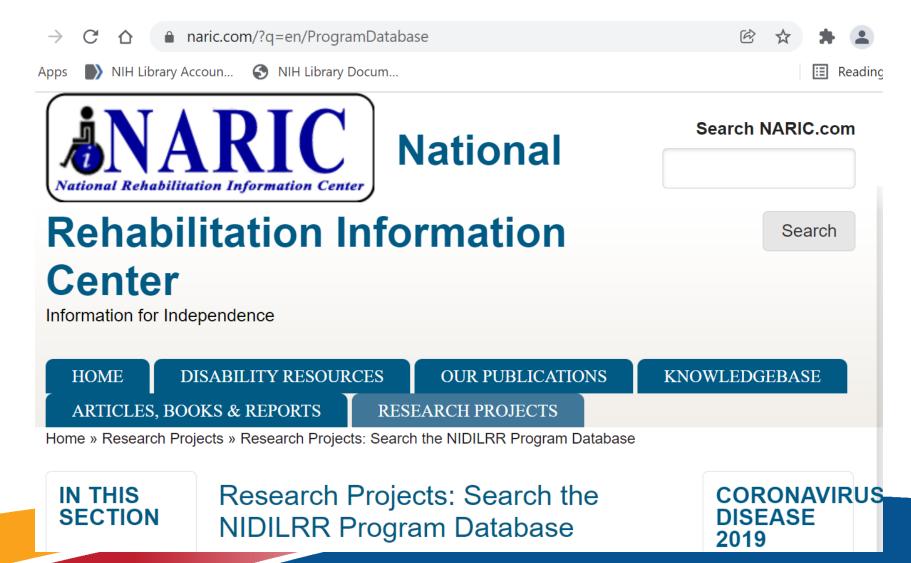
- maintain a positive mood and prevent depression; (Blauwet & Willick, 2012; Campbell & Jones, 1994; Shephard, 1991)
- feel more included and empowered in their communities (Forber-Pratt, 2015)
  - connect with positive mentors and peers with SCI (Groff, Lundberg & Zabriskie, 2009)
- hold a steady job (Blauwet ét al., 2013)
- have positivé disability identity (Anderson, 2009; Forber-Pratt, Scott & Driscoll, 2013; Forber-Pratt, 2015)
- have less secondary health complications / hospitalizations (Slater & Meade, 2004)

- One hundred and thirty-one participants were studied.
  - Analysis shows that playing an additional year of adaptive sport is associated with an approximately 4% increase in likelihood of employment. (Lastuka & Cottingham 2014)
- Exploring women with disabilities link of sport to employment:
  - Having confidence enabled these women to instigate a workplace relationship management strategy appropriate for their employment context. The actions included the disclosure of their disability, to be assertive, and/or to advocate, initiate and educate managers and colleagues in the workplace. (Hanlon & Taylor, 2022)

#### Scoping review:

The research identified 2796 hits. Of which, 23 published between 1992 and 2019 met eligibility criteria. Seven studies identified a direct association between exercise and sport participation with employment and full-time positions. Sixteen studies reported on improved health/work-related outcomes such as occupational performance (i.e., self-care, functional independence), physical fitness (i.e., upper extremity strength, endurance) and psychological well-being (i.e., self-efficacy). (Varahra et al., 2021)

#### **NARIC**



#### Adolescent Disability Identity Conceptual Framework

Adapted from Forber-Pratt et al., 2020 Externalization of Internalization of Context **Disability Identity Disability Identity** · Perpetual negotiation of Relationships with other disabled disability peers Adolescent · Affirmative meaning-making · Relationships with other non-Disability of disability disabled peers · Frustrations about disability Other relationships (e.g., school Identity · Hypothetical Scenario: The family, wider disability Magic Pill community)

Forber-Pratt, A.J., Minotti, B., Burdick, C.E., Brown, M.K., Hanebutt, R.A. (2021). Exploring disability identity with adolescents. Rehabilitation Psychology. https://doi.org/10.1037/rep000041110.1037/rep0000411

### Relationships with Disabled Peers

"I have so many friends from like running para athletic or whatever that I've found. I love that they are like my best friends ever. It's really cool to have friends that are just like normal friends. People that like, they kind of understand the struggle a little bit in a way. It's just that like, if we go like swimming, for example, like I feel more comfortable taking off my leg or I'll feel more comfortable doing the things that I usually have to do that they would understand. I just like wouldn't be as weirded out by it if you know what I mean?" (Sophia, Age 15)

"I feel like you can talk to your friends with disabilities about more stuff because they understand it....Like just doing anything, like walking around, they understand that it's not easy. Just anything. It's just easier to talk about to people with disabilities because they can understand. They have the same going on too, it's not like [that] when you talk to a person who doesn't have a disability and they can run around and stuff. When you say, "Do you know what I'm talking about?" and they'll be like, "No. I don't know what you are talking about." With people with disability, they're like, "Do you know what I'm talking about?" They're like, "Yes, I know what you are about," because you're going through the same stuff." (Teresa, Age 15)

Forber-Pratt, A.J., Minotti, B., Burdick, C.E., Brown, M.K., Hanebutt, R.A. (2021). Exploring disability identity with adolescents. Rehabilitation Psychology. https://doi.org/10.1037/rep000041110.1037/rep0000411

#### **Participants**

- 15 interviews
  - athletes with disabilities (n=8)
  - coaches (including one parent-coach) (n=2)
  - program coordinators (n=4)
  - parents (n=1)
- The types of disabilities represented included:
  - paralysis from birth, polio, amputation, and paralysis due to an accident

Pseudonym	Country	Role
Jane	2 N	Athlete/Paralympian
Tano	*	Athlete/Paralympian
Antobam	*	Athlete/Paralympian
Abeeku	*	Athlete
Amir	*	Athlete
Amy	***	Coach
Linda	No.	Parent
John	***	Program Coord.
Kip	- W	Coach/Parent
Coujoe	*	Athlete
Tina	N. O	Program Coord.
Mensah	*	Athlete/Paralympian
Tim	*	Program Admin.
Jamie	Ĭ	Program Coord.
Sophia	Ĭ	Athlete

#### **Summary of Work**

- Been involved with Bermuda and sport development for PWD since 2009
  - Total of four trips to Bermuda, plus numerous meetings in other locations around the world and on-going consulting
  - Involved with teaching sport clinics, coaches education, supporting development of five Paralympic sports
- Members of research team been involved with Ghana and sport development for PWD since 2001
  - Included both work on the ground in Ghana and bringing athletes/coaches to US for education and training purposes
  - Involved with teaching wheelchair track clinics, meeting with high level officials, making recommendations to existing disability organizations and serving as on-going consultants
- Went to **Zambia** as part of U.S. State Department Sport Envoys Program in April 2017
  - Programming in conjunction with Zambian Paralympic Committee, Special Olympics Zambia and the Zambian U.S. Embassy
  - Two-day clinics in both Ndola and Lusaka (capital)
  - Involved with teaching practical wheelchair track and running clinics, workshops and content for coaches, athletes and teachers, meeting with high level officials, making recommendations to existing disability organizations and serving as on-going consultants

#### Results

- Benefits to One's Perception of Self
  - Internalized identity changes
  - Outward expressions of abilities
- Benefits to Other's Perceptions of Disability
  - Sport-specific changes in perceptions of athletes with disabilities
  - Recognition of broader non-athletic capabilities
- Sense of Civic Responsibility
  - Desire to give back to own community
  - Challenges of the spotlight
  - Becoming a role model for others

#### **Examples from ATHLETES**

- "You know, it [sport] gave me a sense of identity and really brought out who I am." (Jane, Bermudian Paralympic Athlete, Track & Field)
- "I am confident now. I want to change people perceptions about people with physical disabilities. The talent I have is one of the tools that I have can do that." (Coujoe, Ghanaian Paralympic Athlete, Cycling)
- "Now my family talks to me. . . We've passed through obstacles and made it. I have changed; I am stronger. Through this, we are changing the perceptions of persons with disabilities in Ghana." (Abeeku, Ghanaian Paralympic Athlete, Wheelchair Racing)
- "My voice and the other athletes, when we speak on radio and on TV our voices are heard. We are the voice for the voiceless. Aside, people are now valuing us people are now giving us that respect, pointing their hands saying that this guy is a star, you are a star, keep it up. "(Coujoe, Ghanaian Paralympic Athlete, Cycling)

#### **Examples from ATHLETES**

- "I may have a bright future, a brighter future, because of sport." (Sophia, Zambian Paralympic Aspirant, Track & Field)
- When did you start wheelchair racing?] "When I was at school. Yes...When I was in grade five...There was a teacher who was in charge of the sports who was, let me say to be specific, with wheelchair racing...And among those, I was identified. I grew up with it until I graduated...I completed my grade twelve. Yes. I used to participate and to compete with other schools like right here in Zambia.. So among those schools, I used to beat them, you see...And then the time I was in grade 10, I was picked. Yes. I was picked to go and attend the intercom relay in Lusaka. ... But then, after I completed school, I became a bit down due to lack of sponsorship." (Sophia, Zambian Paralympic Aspirant, Track & Field)

#### Pipeline

- Paralympic sport is less developed, relies on adapted and recreational sport for people with disabilities to move to high performance sport
- Lacks a clear pathway to high performance elite sport that has already been established for non-disability sport
- Rec teams to competitive youth teams to high school to college/uni --- this could be a unique tie with disability services – providing structure, but also need coaching, equipment
- Need a well funded and established coaching system and coaches to be invested in disability sport and the Paralympic movement
- Equipment costs
- Athlete supports (i.e., personal care, guides)
- Longterm athlete development makes the sell of job benefits, health benefits and leadership skills learned

### Types of Sport Participation in the U.S.

#### **Sports and Recreation Types:**

- Community-based and non-profit organizations
- State Parks and Recreation Association
- Public and Private Schools
- Colleges and Universities
- Clubs
- Professional Sports

There are multiple opportunities to participate recreationally and competitively. In the U.S., the government is typically not involved with these options.

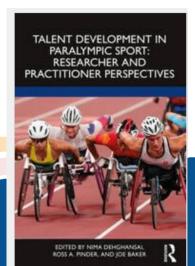
## Athletes – Considerations When Selecting a Sports Program

- Do I want recreational or competitive sports? If competitive, how competitive?
- Do I want an individual sport or a team sport?
- Do I want to participate in an adaptive sports program with individuals with a disability or in a general sports program that includes individuals with and without a disability? Or both?
- What are my goals in regards to participating in sports and recreation?

### Long-Term Athlete Development Models

- Canada: <a href="https://sportforlife.ca/wp-content/uploads/2016/06/NAC\_ENGLISH\_SCREEN\_rev2013.pdf">https://sportforlife.ca/wp-content/uploads/2016/06/NAC\_ENGLISH\_SCREEN\_rev2013.pdf</a>
- United States:

   https://www.teamusa.org/About-the USOPC/Coaching-Education/American Development-Model
- Other Resource:



#### Talent Identification

- Some countries have more formalized processes and models
- Research is lacking in this area; systematic review (Dehghansai et al., 2017)

### Systematic Review Findings (Dehghansai et al., 2017)

Table 2 Total Number of Appearances of Sports and Impairments in the Included Studies

Sport	Appearances, n	Impairment	Appearances, n
Wheelchair basketball	8	Spinal-cord injury	9
Track and field	6	Amputation	6
Swimming	4	Postpolio	3
Road racing	3	Paraplegia	3
Wheelchair rugby	2	Spina bifida	2
Wheelchair tennis	1	Visual impairment	2
Sledge hockey	1	SCF	1
Hand cycling	1	Poliomyelitis	1
Cross-country sledding	1	Cerebral palsy	1
Cross-country skiing	1	Muscular dystrophy	1
Shooting	1	Multiple sclerosis	1
Archery	1	Mental impairment	1
Table tennis	1	Quadriplegic	1
Weight lifting	1		

*Note.* SCF = spinal compression fracture.

#### International Charters & Policies

- Council of Europe formulated a policy on Sport For All which was passed in 1976 declaring that every individual shall have the right to participate in sport.
- The United Nations Education Science and Cultural Organization (UNESCO) adopted an International Charter of Physical Education and Sport in 1978 which stated that every person is entitled to participate in sport, including specifically women, young people, the elderly and those with a disability.

#### International Charters & Policies

- The Council of Europe extended their recognition of the right to participate in sport and created the Sport for All: Disabled People charter in 1987
- The UN developed the United Nations Standard Rules on the Equalisation of Persons with Disabilities in 1991

#### International Charters & Policies

- United Nations enacted a comprehensive legislation called the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006 to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities.
  - Article 30.5: specific legislation on the rights of people with a disability to participate on an equal basis with others in recreational, leisure and sporting activities.

#### **U.S. National Policies**

**Table 30.3** Legislation promoting universal access to sport and fitness opportunities

Section 504 of the Rehabilitation Act  1. Equal disabilities and the second of the the sec	es access guidelines to federal buildings and eral facilities constructed with federal grants or loans access and opportunity for individuals with ities to the same programs, services, and venues d by all persons fational parks ederally supported programs offering fitness
Rehabilitation Act  disabilitation Act  (a) M  (b) H  (c) C  (c) F  Americans with Disabilities  Act (ADA)  1. Bans of emplo  2. Ensure transp	ities to the same programs, services, and venues d by all persons ational parks ederally supported programs offering fitness
Act (ADA) emplo 2. Ensure transp	pportunities rivately owned gyms and health clubs are excluded
	iscrimination on the basis of disability in ment and education s accessibility of newly built infrastructure and ortation systems ntry ramps accessible bathroom facilities accessible locker rooms
Education Act (IDEA) (reauthorized 3–21 y	rdizes special education for youth with disabilities ears of age es participation in physical education
Federal Guidance Notification interse	s equal access to extracurricular athletics, club, and holastic (varsity) athletics in schools receiving federal g at all educational levels
Equity for Students with  Disabilities Act  (a) E  (b) E  2. Count to allo	s access to public school interscholastic athletic ms for youth with disabilities in Maryland qual opportunity to participate in physical education qual opportunity to try out for athletic programs y schools must provide reasonable accommodations w participation to the fullest extent possible y schools must provide alternative physical education

(Mascarinas & Blauwet, 2018)

#### **Continuum of Inclusion**

Inclusion as forced compliance, or physical sharing of space of persons with and without disabilities but lacking in true programmatic inclusion.

Individuals from specific disability groups included in programs or services but lacking in interaction with individuals without disabilities and those outside their own disability group.

Partial inclusion of individuals with any disabilities in some aspects of sport, recreation, living, community, employment, education and society.

Full inclusion of individuals with and without disabilities in all aspects of sport, recreation, living, community, employment, education and society.

Inclusion is embraced as the norm and seen as a catalyst for growth.

(Forber-Pratt & Lyew, 2020)

#### Conclusions

- Participation in sport paves way for athletes with disabilities to become contributing members of society and leaders.
- These individuals use sport as a vehicle to change perceptions and stereotypes about disability.
- Sport can be a catalyst for social change
- Paralympic, adapted, disability sport should not be an afterthought or an add-on; it **must** be fully integrated into all governance structures, programmatic activities, long-term visions/goals
- Having policy is not enough.
- Use the continuum of inclusion to assess where are you at today vs. where do you want to be?
- For each sport initiative and research project being undertaken, what is the corresponding the adapted sport piece alongside?

### International Opportunities w NIDILRR

- Hosting or participating in international research meetings/conferences/consultation discussions
- NIDILRR grantees have initiated some of this presence
- Site visits with international disability researchers or university programs or disability-specific sites in other countries
- Contributing to international research agenda documents for the field of disability and rehabilitation
- Organized convening on women with disabilities in other countries and research in the past
- Sharing of NIDILRR disability and rehabilitation research findings with other government colleagues in countries with similar disability research interests or responsibilities

### International Opportunities w NIDILRR (cont.,)

- Providing consultation to foreign government officials about the importance of disability and rehabilitation research and how to embed within policy
- Opportunities for international scholars to apply for funding through Switzer (if able to receive Federal dollars and be U.S. based and meet visa requirements or to participate in Fulbright program
- NIDILRR has hosted Fulbright scholars in the past and will be hosting Fulbright scholar in Fall 2022 (delayed due to COVID)
- If international NGO has a US-based entity, are eligible to receive federal funds and to apply to all competitions.
- Potential to co-sponsor international disability research events

Name of Funding Age	nc

#### **National Institute on Disability and Rehabilitation** (NIDILRR) in Administration for Community Living (ACL)

Studies that advance long-term outcomes that promote the

capacity for individuals with disabilities to fully participate in

Agency Characteristics	

**US Federal** 

Types of Research Supported and **Priorities** 

> society, such as independence, community participation, and employment. Research studies that explore the complex interactions among personal, societal, and environmental factors. These focuses can be cross-disability, or specific disability types and populations

Psychosocial Research Funding Mechanism and Programs

Psychosocial research supported in all NIDILRR funding mechanisms

Funding Available Number of Awards Funded during

the past year

1,400 unique projects in FY21

80 awards funded in FY22

276 awards in active portfolio in FY21

\$118M

Contact Information

Mechanisms for Foreign Investigators Funding	

Research Impact Who

benefits? How?

Projects should impact people with disabilities, including those with the greatest support needs and related systems and environments that they interact with. Applications should include input of disabled individuals throughout the proposed work.
Foreign organizations are not eligible to apply for or receive NIDILRR grants.
Foreign organizations may receive NIDILRR funding as subawardees on grants made to organizations in the U.S.
Foreign investigators may serve as investigators on NIDILRR grants, either as employees of grantee organizations in the U.S. or as employees of foreign subawardees.
U.Sbased foreign investigators may apply for and receive Switzer Research Fellowship Grants. All applicants must have a U.S. Social Security Number in order to apply.
Foreign investigators are eligible for Fulbright scholar participation with NIDILRR.
NIDILRR-Mailbox@acl.hhs.gov

#### Possible Exploration

- NOSI: Academy of Finland (AKA) National Institutes of Health (NIH) Partnership Program
  - The AKA-NIH Partnership Program seeks to encourage increased collaborative research between investigators in the U.S. and Finland. This is to be facilitated through the submission of grant applications from U.S. institutions that include collaboration with Finnish investigators selected by AKA to participate in the joint research program.
- https://grants.nih.gov/grants/guide/notice-files/not-od-21-021.html
- https://www.aka.fi/en/research-funding/programmes-andother-funding-schemes/flagship-programme/

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