# **Getting the Message Across!**

Tips and Tricks for Developing and Disseminating Physical Activity Information for Families of Children with Disabilities





# Introductions







Nancy Huynh



Andrea Nelson



# How did we get here?

- > OPC Continuing to Play Project
- Community Insight Group for Adaptive Sport (CIGAS)
- Collected feedback from the community
  - Over 40 parents surveyed
  - Lack of communication and awareness between organizations/programs and families of children and youth with disabilities
  - Connected with Rebecca about her work in this area



# **Canadian Disability Participaction Project**



An alliance of university, public, private and government partners working to enhance community participation among Canadians with disabilities.



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### **Graduate Students**

Victoria Larocca

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Sunita Tanna

**Ritu Sharma** 

Alexandra Walters



# SSHRC

Social Sciences and Humanities Research Council of Canada



# Why are Language and Program Information Important?

It is a fact that we can design extraordinary and innovative programs that are exceptionally "accessible" and "inclusive" and, purposefully guide "quality participation" as the outcome.

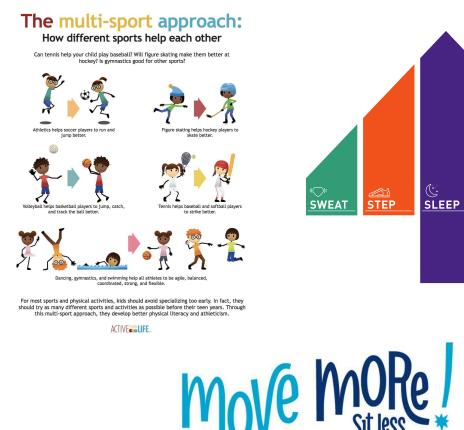
It is also a fact that most organizations fail horribly at recruiting participants and conclude that there is little community interest or no demand. We know that's not accurate and that in fact, communication (or poor, uninformed or inappropriate communication) is the main reason.

Your work will provide community clubs with evidence-based knowledge, guidance and tools to effectively reach, engage and mobilize parents of children with disabilities!! This will be a game-changer at the grassroots!!

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# Physical activity promotion and information is a problem!

SIT



Adapted Physical Activity Quarterly, 2019, 36, 185–201 https://doi.org/10.1123/apaq.2018-0020 © 2019 Human Kinetics, Inc. Human Kinetics

### Improving Communication of Information About Physical Activity Opportunities for People With Disabilities

Eva A. Jaarsma, Damian Haslett, and Brett Smith University of Birmingham

Disability, the communication of physical activity and sedentary behaviour, and ableism: a call for inclusive messages

Brett Smith <sup>(D)</sup>, <sup>1</sup> Kamran Mallick, <sup>2</sup> Javier Monforte, <sup>1</sup> Charlie Foster<sup>3</sup>

# Ask the experts!

Research in Developmental Disabilities 64 (2017) 37-46



Research in Developmental Disabilities

### Targeted physical activity messages for parents of children with disabilities: A qualitative investigation of parents' informational needs and preferences



R.L. Bassett-Gunter<sup>a,\*</sup>, R.J. Ruscitti<sup>a</sup>, A.E. Latimer-Cheung<sup>b</sup>, J.L. Fraser-Thomas<sup>a</sup>

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# **Key Findings**

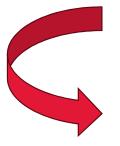
Preferences Regarding Message Content	<ul> <li>Targeted information</li> <li>Inclusive images and belongingness</li> <li>Self-regulatory tools and strategies</li> </ul>	<del>ب</del>
Challenges	<ul> <li>Lack of targeted information</li> <li>Confusion of "inclusive" and "accessible"</li> </ul>	- Q
Preferred Methods and Sources of Information	<ul> <li>Other parents and narratives</li> <li>Reliable and credible organizations</li> <li>Central "hub" for information</li> <li>Information &amp; messages on the go!</li> </ul>	i

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# Challenges

# Challenges

Confusion of "inclusive" and "accessible"Lack of targeted information



- Language Clarification
- Improved Physical Activity Program Information



#### ORIGINAL ARTICLE

#### ARID bild WILEY

# Using a think-aloud methodology to understand online physical activity information search experiences and preferences of parents of children and youth with disabilities

Tharsheka Natkunam<sup>1</sup> | Lauren Tristani<sup>1</sup> | Danielle Peers<sup>2</sup> | Jessica Fraser-Thomas<sup>1</sup> | Amy E. Latimer-Cheung<sup>3</sup> | Rebecca Bassett-Gunter<sup>1</sup>

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#### Correspondence

Lauren Tristani, School of Kinesiology and Health Science, Faculty of Health, York University, Room 341, 4700 Keele St, Toronto, ON, Canada M3J 1P3. Email: tristani@yorku.ca

#### Abstract

**Background:** The Internet is a preferred source of physical activity (PA) information. However, limited research exists regarding the experiences of parents of children and youth with disabilities (CYWD) in searching for PA programme information online. This research examined the experiences and preferences of parents of CYWD in searching for PA programme information online.

**Method:** Parents of CYWD (n = 10) participated in a think-aloud exercise while searching for PA programme information online. Following the think-aloud exercise, semi-structured interviews were used to further understand parents' experiences and preferences in searching for PA programme information online.

**Results:** Parents identified key features that contributed to a positive online search experience. Additionally, parents noted challenges and resulting negative affect that was experienced.

**Conclusions:** This research can inform the development and dissemination of online PA programme information that is accessible and relevant to the preferences of parents of CYWD and can facilitate positive search experiences.

#### KEYWORDS

disability, information seeking, parents, physical activity, think aloud, youth



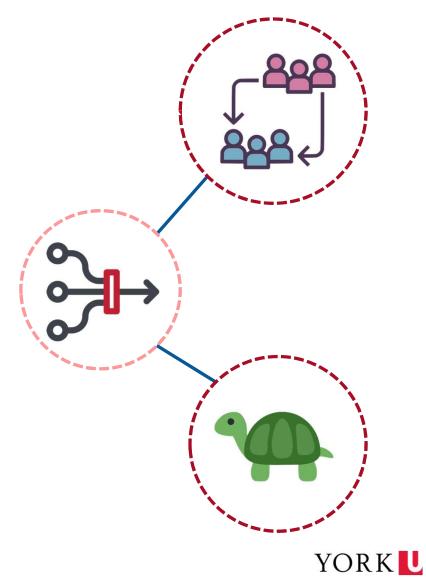






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- > Community partners are looking for guidance
- > Streamline efforts
- Research moves slowly!
- > They are the experts!



# Our goals...



**Understand best practices** for communicating physical activity and program information targeting families of children with disabilities



Help community-based organizations Communicate physical activity and program information to promote various forms of physical activity for children with disabilities





# **SSHRC Connection Grant**

The primary objective: establish evidence-informed recommendations for the development of physical activity information targeting families of children with disabilities

**GUIDING PRINCIPLES:** 

- Understand the evidence.
- Co-create: Engage researchers and knowledge users to exchange knowledge.
- Develop and produce tools for knowledge users.
- Strengthen partnerships among researchers and knowledge users.

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## How does one do this?

### Appraisal of Guidelines, Research, and Evaluation II (AGREE II)

- Gold standard for guideline assessment, development, and reporting
- Supports evidence-based guideline development
- Promotes rigour and transparency

Ginis et al. BMC Public Health (2017) 17:209 DOI 10.1186/s12889-017-4090-5 BMC Public Health	Spinal Cord (2013) 51, 491–500 © 2013 International Spinal Cord Society All rights reserved 1362-4393/13 www.nature.com/sc	
RESEARCH ARTICLE       Open Access         Formulation of evidence-based messages       Image: Construct of the second seco	ORIGINAL ARTICLE Development of an evidence-informed leisure time physical activity resource for adults with spinal cord injury: the SCI Get Fit Toolkit KP Arbour-Nicitopoulos <sup>1</sup> , KA Martin Ginis <sup>1</sup> , AE Latimer-Cheung <sup>2</sup> , C Bourne <sup>3</sup> , D Campbell <sup>4</sup> , S Cappe <sup>5</sup> , S Ginis <sup>6</sup> , AL Hicks <sup>1</sup> , P Pomerleau <sup>7</sup> and K Smith <sup>8</sup>	
Mental Health and Physical Activity 17 (2019) 100297         Contents lists available at ScienceDirect         Mental Health and Physical Activity         pournal homepage: www.elsevier.com/locate/menpa	RESEARCH ARTICLEOpen AccessEvidence-informed recommendations for constructing and disseminating messages supplementing the new Canadian Physical	
It's more than just a referral: Development of an evidence-informed exercise and depression toolkit Krista Glowacki <sup>a,*</sup> , Kelly Arbour-Nicitopoulos <sup>b</sup> , Meghan Burrows <sup>c</sup> , Leslie Chesick <sup>d</sup> ,	Activity Guidelines	
Lyn Heinmann <sup>6</sup> , Stahl Fring <sup>6</sup> , Raymond W. Lam <sup>1</sup> , Soultana Macridis <sup>8</sup> , Erin Michalak <sup>h</sup> , Aidan Scott <sup>1</sup> , Adrian Taylor <sup>1</sup> , Guy Faulkner <sup>8</sup>	Kristina Kowalski <sup>2</sup> , Gabriella Nasuti <sup>2</sup> , Marie-Josée Perrier <sup>1</sup> , Mary Duggan <sup>6</sup> and The Canadian Physical Activity Guidelines Messaging Recommendation Workgroup	

# **Recommendations To Guide The Development Of Physical Activity Information Targeting Families Of Children with Disabilities**

AGREE II: Appraisal of Guidelines, Research and Evaluation



PARAMETERS



SYSTEMATIC SCOPING REVIEW



EXPERT PANEL MEETING



STAKEHOLDER SURVEY

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	81			

FINAL RECOMMENDATIONS

# **Scope and Purpose of the Recommendations**



Assist <u>organizations</u> in developing evidence-based physical activity information for families of children with disabilities



# **Practical Questions Addressed by the Recommendations**





What physical activity information should organizations provide to families of children with disabilities?





# Users of the Recommendations

Organizations (or individuals) that promote, support and/or deliver physical activity to children with disabilities







#### Review

#### SYSTEMATIC SCOPING REVIEW

# **Developing and Disseminating Physical Activity Messages Targeting Parents: A Systematic Scoping Review**

Victoria Larocca<sup>1,\*</sup>, Kelly P. Arbour-Nicitopoulos<sup>2</sup>, Jennifer R. Tomasone<sup>3</sup>, Amy E. Latimer-Cheung<sup>3</sup> and Rebecca L. Bassett-Gunter<sup>1</sup>

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# Language and Concept Clarification

### Rationale

 Parents desire clarity around language used in physical activity messages and information



PHYSICAL ACTIVITY ACCESSIBLE INCLUSIVE ADAPTED PHYSICAL ACTIVITY INTEGRATED PHYSICAL ACTIVITY

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# Language and Concept Clarification

### **Key Limitations**

????

o Lack of:

Evidence-based disability specific guidelines

Universal definitions of terms

 Research on the effects of providing information to parents regarding definitions and concepts



# **Physical Activity Program Information**

### Rationale

- o Lack of targeted information
- Parent frustration
- o Lack of targeted information negatively affects parent support behaviours
- Search terms, website organization and technical features, and specific program information
- o Credibility: program and staff
- Easily accessible important program information





# **Physical Activity Program Information**

### **Key Limitations**

No known research regarding best practice







### **Meeting Attendees**

Researchers

N=28

- Student Trainees
- Leaders in child physical activity promotion
- Leaders in physical activity delivery for children with disabilities
- Experts in knowledge mobilization
- · Parents of children with disabilities









### Sectors represented by Knowledge Users



Recreation

Disability



Health promotion



Health care





Provide families of children with disabilities with:

1. Clear and consistent definitions of terms such as physical activity, adapted, accessible, integrated, and inclusive.

2. Clear and detailed information about your physical activity programs, staff and facilities.



# LANGUAGE CLARIFICATION

Consistency and clarify are key!

> There is no one "CORRECT" definition

- > Particularly unclear terms
  - Inclusive
  - Adapted
  - Integrated
  - Accessible

> What does this actually mean in the context of your program or space?

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# **LANGUAGE CLARIFICATION – Clear as mud?!**

### > Inclusive Physical Activity:

• same opportunity for children and teens with and without disabilities to participate in the same activity

### > Adapted Physical Activity:

• adapted or modified activities to allow for full participation by children and teens with particular disabilities

### > Accessible:

 programs and spaces that have the flexibility to accommodate each child's needs and preferences regarding physical activity

#### > Integrated Physical Activity:

- designed for children without disabilities modifications may be provided to support children with disabilities
- unlike inclusive physical activity programs that are designed to provide the same opportunity for children and teens with and without disabilities to participate



# LANGUAGE CLARIFICATION

> Aspects of inclusion, adapted, accessible, integrated physical activity

> Examples of these types of programs

> Take home point: What do you mean within the context of your program or organization?



# PHYSICAL ACTIVITY PROGRAM INFORMATION

> Parents do not want to spend three hours looking for a physical activity opportunity for their child!

> More information is better – easy to find

> Better communication with families means more success for your program and being better prepared to meet the needs of children who participates



# PHYSICAL ACTIVITY PROGRAM INFORMATION

## > WHO

- organization
- contact information
- staff

## > WHAT

- Program activities
- Populations served
- Reviews from participants and families
- Supports available
- Cost
- What to bring

# > WHERE

- Description of facilities
- Transportation options

## > WHEN

- Program schedule and timing
- When was website/information last updated





and Disseminating Physical Activity Information for Families of Children with Disabilities

SPORT CANADA



Assisting, Informing and Motivating Physical Activity

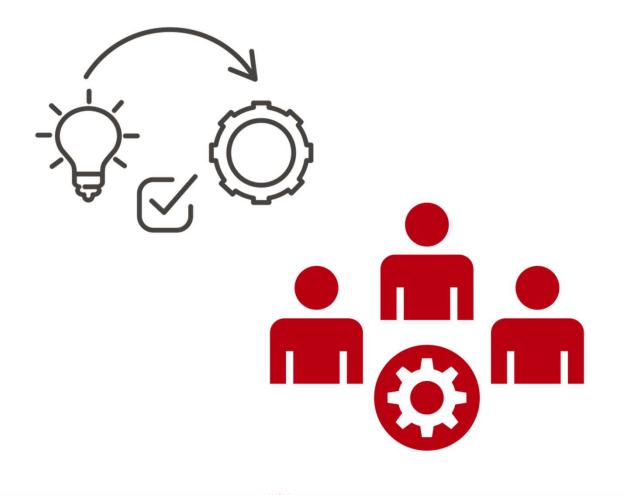
Image Description: Two children in a gym with a group of people playing basketball. One kid is wearing a hat and holding a



# WWW.AIMPA.CA



How to implement these in your own organization....



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### **Step 1: Which recommendation is most relevant to your organization?**

Think about how language and program information are important within your organization or your experiences working with people with disabilities in physical activity settings, and pick one of the following recommendations:

- 1. Clear and consistent definitions of terms such as physical activity, adapted, accessible, integrated, and inclusive.
- 2. Clear and detailed information about your physical activity programs, staff and facilities.



# **Step 2: Who is your target audience?**

- > Who do you want to reach?
- > Any special considerations for reaching your target audience?





# **Step 3: Implementation Exercise**

Recommendation 1: The goal is to provide families with clear and consistent definitions of terms such as physical activity, adapted, accessible, integrated, and inclusive.

> A. Brainstorm a list of terms that are relevant to your organization.

Think of any terms that do not have a clear definition or terms that parents and others outside our sector may not be familiar with.

B. Choose at least one important term and consider how you would define this term in the context of your organization?

Are there any aspects of the term(s) or concepts that are unclear to you? How could you clarify these for your audience?

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# **Step 3: Implementation Exercise**

Recommendation 2: The goal is to provide families with clear and detailed information about your physical activity programs, staff, and facilities.

- A. Using the Accessible Physical Activity Information Checklist, conduct an "audit" of your organization's program information available online. If this does not apply to you, look for a program for children with disabilities online to use for this exercise.
- **B.** What is missing? Draft content for missing information.



# **Step 4: How can you reach your target audience?**

- > How can you ensure credibility with your target audience?
- Consider user-friendliness! How can you deliver this information to your audience in a user-friendly way?
- What strategies will you use to deliver this information to your target audience? Are there multiple strategies you could consider?
- Have you considered accessibility of the information or promotion material? What strategies can you use to support accessibility?



# **Step 5: What tools or resources do you need?**

# What tools or resources would make it easier for you to implement these recommendations?

Imagine you're being tasked with the specific job of implementing these recommendations within your organization. What tools and resources could make this easier for you? Use your imagination! Imagine there are no limits to what is possible!



# Let's give it a try!

## **Recommendation 1: Language Clarification**

- Worksheet
- Language Clarification Tips Sheet

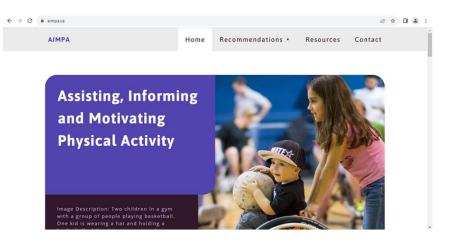
### **Recommendation 2: Physical Activity Program Information**

- Worksheet
- Physical Activity Program Information Checklist



# Sharing, Reflections and Wrap Up

> More Information: www.aimpa.ca





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