

## ISWP Advocacy Working Group

### 03/23/2015 Meeting Recap

The ISWP Advocacy Working Group met by conference call on 03/23/2015 from 12:00 p.m. to 1:00 p.m. U.S. Eastern Time. This provides a recap. Participants' list appears at the end.

**Link to Meeting Recording:** <https://pitrstce.adobeconnect.com/p913qe5n8jf/>

**Next Meeting:** Thursday, April 30, 12:00 p.m. U.S. Eastern time.

#### **Action Items:** (including due dates and responsibility)

1. Review objectives discussed in the meeting. (Document attached to this message; All WG members to review by **Monday 4/27.**)
2. **Jon Pearlman** will ask Matt McCambridge for a contact or contacts involved in malaria or water awareness campaigns.

#### **Discussion:**

*Background:* Michael described the Advocacy Working Group mission. WG participants introduced themselves.

Mary explained ISWP officially launched at the International Seating Symposium (ISS) at the end of February 2015. During a meeting at ISS, the ISWP Advisory Board agreed four Working Groups would be established to support the two-year work plan objectives: Standards, Advocacy, Training, and Membership & Coordination.

Advocacy will help support each of the working groups and will focus on developing mechanisms for educating the public.

Objectives for the Advocacy WG:

- Develop and deploy our advocacy campaigns (website, social media)
- Run and coordinate international and national advocacy campaigns
- Coordinate advocacy sessions at conferences



There will be a Google Group where we will be developing and sharing documents and providing a mechanism to communicate with the group.

WG meetings will be recorded and open to the public; we will also send meeting recaps by e-mail.

*Five-year Vision:* WG members were invited to answer the question: *Looking 5 years ahead, what impact do we want to have in terms of advocacy for wheelchair (WC) professionals?* Feedback:

**Michael Allen:** There's a huge need and too few groups working on it. The awareness and budget in this subject is low. Possible objectives:

1. Expanding the global awareness of the need.
2. Increasing the size of the "community" engaged with the issue – Example: Indonesia – we are working with the government there to start funding wheelchairs. They asked how other countries have done that; we don't have a lot of evidence to show that.
3. Providing necessary resources and tools for local advocacy efforts.
4. Engaging and education more donors.

**Chris Lewis:** In his experience, raising awareness has effected changes in local governments, making WCs more accessible for the local community. Example: Baja California, Mexico.

The ability to go to donors and present data from specific areas can help obtain more resources and funding. We need evidence-based information for donors and sharing of resources.

**Jon Pearlman:** The ISWP Standards Working Group is establishing a strategy for collecting data. The plan is to display on a map where WCs are and where WC provision is occurring. In the next quarter we will include the information on the website, feasible data for people to use.

**Mary Goldberg:** Education is the gateway for engagement.

**Jon:** In terms of goals of this working group (advocacy), the focus is how data should be presented; e.g., fact sheets, visualization, that help understand the needs of the WC sector. In The Standards WG can work with partners in collecting data.

*Additional Objectives:* Michael invited the group to provide additional goals/objectives:

**Eric Wunderlich:** Increase resources and funding so new legislation can be enacted and contributions/donations increased. Consider quality of services in the provision of WC, implementing guidelines and increasing awareness of how to address the need.

**Miriam Zisook:** As a designer, she thinks about the role of good design on an individual's needs, environment, different social and interpersonal considerations. She hopes to play a role in creating and disseminating best design practices, in addition to promoting more spending and wheelchair access.

**Mary:** There is an ISWP Student Organization at the University of Pittsburgh hoping to serve as a model for universities internationally.

*Additional WG Resources:* Other people were mentioned as important to be part of the group:

- Someone who has been involved in water or malaria campaigns. Matt McCambridge worked on water purification project at DEKA. **Jon** will see if he has a good contact in that field.
- Someone from Vida Independiente.

*Additional comments from Advocacy WG members following the call – received by phone/e-mail:*

**Hisaichi Ohnabe** shared with us the paper “Flying Wheelchair Voluntary Activity” (attached).

**Don Schoendorfer** finds important:

- Promote and focus on the goal of 20/20/20
- Create PR campaigns that will increase awareness on the issue and the impacts of providing wheelchairs.
- Find a spokesperson for the issue who people can connect with
- Collect important research data connected to the impacts of wheelchairs which will, in turn, increase donors’ interest
  - Ensure research is done outside of organizations to limit views of bias
  - Focus on research that shows cost benefits to providing wheelchairs (e.g., Reduction in # of days in hospital, total cost for care, job creation)
- Create fundraising and marketing tools that can be shared across organizations
- Collaborate within the industry to focus on a single country to solve the problem
- Bottom line – get more \$ into the industry

**Eric** would like to see:

- Collection of economic impact to support government advocacy
  - What does the investment in wheelchairs mean to a government? How do they save \$ in healthcare, lost income of caregivers, etc.)
  - Reference a WHO study on the economic impacts of water & sanitation (minimum of \$3 saved for every \$1 investment)
- Example of funding mechanisms governments can adopt – from basic to very complex. Broken into a possible progression.
- Sharable advocacy tools that can be used by all organizations (PPT slides, fliers, ISWP webpage, etc.)
  - Track where & how these tools are used and how they are received
- A country file/webpage. These can be utilized like Wikipedia and allow registered users to add information including:
  - Overview on the current state of wheelchair access & provision
  - Partner information
  - What trainings have occurred
  - Advocacy efforts with specific notes

**Chapal Khasnabis** made the following recommendations:

1. ISWP needs to become recognized as an entity that can advocate on behalf of an issue with the UN, its affiliated bodies and Member States. This means ISWP need to become an independent legal entity and eventually become a registered UN ([CoNGO](#)) or registered with ECSOC/DESA group within the UN.
2. Launch / participate in regional/global workshops/events with groups like RESNA, ISS & ISPO to increase awareness regionally.
  - These workshops can include both the WSTP Stakeholders module and information on how to link with ISWP.
  - Attendees should include Ministry of Health, Ministry of Social Welfare, Associations of providers, DPO's and other user groups.
3. Promote ISWP at all major conferences, congresses and workshops worldwide to gain recognition
  - Leverage members to promote ISWP
4. Create an alliance with other associations and entities that work on related issues
  - Examples are ISPO, WFOT, WCPT, etc.
  - GATE can be used as a facilitator to help this get initiated.
5. Work towards making an impact within the WHO World Health Assembly (WHA)
  - Find a champion to bring the issue up within the WHA
  - Try to get a WHA resolution on AT like WHA resolution on Disability, Aging, Autism, Medical Devices etc.
6. ISWP should focus advocacy efforts at a higher level than its NGO members.

**Antony Dutinne** recommended the following:

1. Before diving into multiple activities, the working group should go through a (strategic) planning process to:
  - Define a clear goal that we are all striving for
  - Create messaging to support the defined goal and ensure the messaging is linked to specific recommendations
  - Outline a roadmap to achieve the specific goals

Without us clearly defining what we are trying to achieve, much of our efforts can become unfocused.

2. Create simple FAQ sheets and basic informational documents to maintain consistency and empower others to advocate on behalf of the issue.

3. Build a group of champions/spokespeople to speak on behalf of the issue. It is important to have both public figures involved and political champions.
  - These champions can be both wheelchair users and non wheelchair users.
  - Creating some agitation and elements of outrage can be very useful in gaining attention.
4. Identify all groups that have an interest in the issue and can become spoke persons for the issue.
  - Educate these groups on the information they need to know and provide them tools and resources needed (FAQ sheet, basic info sheets, etc.).
  - Example group is Global Health Technology Coalition.
5. Learn from the other groups that have gone through a similar process
  - Possible example is Non Communicable Diseases (NCD) Alliance
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6. Have a clear focused message as a wheelchair advocacy network, but then contribute to messaging on wider issues e.g. GATE, rehab coalition and GHTC that go beyond wheelchairs.

**Participants** (check mark indicates participation on call)

✓	Michael Allen, UCP Wheels, <i>Chair</i>
✓	Christine Cornick, Consultant
	Antony Duttine, Handicap International
✓	Ken Johns, Brunner
✓	Chris Lewis, American Wheelchair Mission
✓	Hisaichi Ohnabe, Niigata University
	Don Schoendorfer, Free Wheelchair Mission
✓	Eric Wunderlich, LDS
✓	Miriam Zisook, Perkins School for the Blind
	Chapal Khasnabis, WHO
✓	Mary Goldberg, University of Pittsburgh
✓	Yohali Burrola Mendez, University of Pittsburgh
✓	Jon Pearlman, University of Pittsburgh
✓	Nancy Augustine, University of Pittsburgh

Prepared by:

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