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Supported Leadership
Why it is Important for PWUAAC and ISAAC
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Across the Globe
- New concept of disability
- Expansion of the concept of diversity
- New roles, relationships, challenges, opportunities

A New Cry
- Shum davar le’gabeinu, mi’biladeinu
- Rien sur moi sans moi
- Todo con nosotros, nada sin nostros
- Niks oor my, sonder my
- Azikho izinto ngapahandle kwetho.

Forces have Moved Us to a New Paradigm of Disability
United Nations Convention on the Rights of People with Disabilities ....

...... Becomes International Law
**Disability Rights Movement and the UNConventionRPD:**

Disability is not synonymous with illness or dependency...

**and that**

Disability is as much a function of disabling environments and attitudes as it is physical, cognitive, sensory or communication limitations.

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**New Challenges & Opportunities: New Roles and Relationships**

- Shift in power, roles, relationship between professionals and people with disabilities
- Self determination
- Self Advocacy groups
- Shift in defining “expert”
- “Nothing About Me without Me”
- International Law: UN Convention RPD
- **Leadership!!!!!**

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**International Law: UNRPD**

- **50 Articles**
- Many call for **Leadership Development**

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**Leadership & the CRPD**

- **Article 3 - General Principles**
  - Equality of **opportunity**
  - Full and **effective participation** and inclusion in society
Leadership & the CRPD

Article 6 - Awareness-raising

- States parties undertake to adopt immediate, effective and appropriate measures to:
  - to promote awareness of the capabilities and contributions of persons with disabilities.

Leadership & the CRPD

Article 24 -- Education

- States Parties recognize the right of persons with disabilities to education... Ensure an inclusive education system at all levels and life long learning...
  - Without discrimination and on an equal basis with others,
  - With reasonable accommodations.

Leadership & the CRPD

Article 29 -- Participation in political and public life

- States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others...
  - (b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs...

What IS a Leader???? What IS Leadership????

Different definitions
A Leader is.....
- a person who rules, guides or inspires others to follow;
- a person with vision;
- a person with integrity, passion, empathy, courage, and “know-how”

Leadership.....
- Is a process by which a person influences others to accomplish an objective or directs the organization in a way that makes it more cohesive and coherent;
- makes the followers want to achieve high goals, rather than simply bossing people around.

Who Are Some Leaders We Know? Who is this Leader?

Martin Luther King
He was a great American civil rights leader.
Who is this Leader?  

**Mahatma Ghandi**

He was a great Indian leader who taught us how to effect change through passive resistance.

Who is this Leader?  

**Golda Meier**

She was a Prime Minister of Israel and had to lead the people of Israel through a very difficult war.
Who is this Leader?

Nelson Mandela
After spending more than 25 years in prison, he was the first freely-elected president of South Africa after the end of Apartheid.

Do You Know Who This Leader Is?

Ed Roberts
http://www.disabilityhistorywiki.org/leadership/
Meredith Allen

From Melbourne Australia, Meredith has been a consistent leader in AGOSCI and ISAAC. She has introduced the idea of an AAC culture.

Michael Williams

Michael is the “granddad” of AAC in the US, the editor of Alternatively Speaking, and a partner in the RERC.
Who is this Leader?

Martin Pistorious

- Originally from South Africa, Martin now lives with his wife in the England
- Martin is an author
- Frequently testifies before Parliament about the rights of people who with limited or no functional speech

Who is this Leader?

Faye Warren

- Mentor
- Teacher
- Organizer of AAC Awareness Day
- ISAAC PWUAAC Chair
- Member, ISAAC EC
Who is this Leader?

- Originally from South Korea,
- Now lives with her own family, husband and two kids, in the U.S.
- Assistant professor at George Mason University
- The first person with Cerebral Palsy in Korea who earned a doctoral degree abroad
- Teaches special education graduate courses using AAC at GMU

Yoosun Chung

- One of the winners of the 2012 Teaching Excellence Award at George Mason University
- Author – published several books in Korean. *Title: Miracles do not come miraculously*
- Often present as a keynote speaker or as a guest speaker, at organizations, her kids school, girl scout meeting, etc.

Yoosun Chung

- Originally from South Korea,
- Now lives with her own family, husband and two kids, in the U.S.
- Assistant professor at George Mason University
- The first person with Cerebral Palsy in Korea who earned a doctoral degree abroad
- Teaches special education graduate courses using AAC at GMU

Miracles do not come Miraculously!!!

- Person’s will
- Society (Law, Attitude, Active volunteer work)
- Family (Parents, Siblings, Spouses, Children)

A little Miracle
Leadership & ISAAC

Why is it important to have PWUAAC as leaders in ISAAC?

- Increase membership in ISAAC
- Primary stakeholder
- Provide relevant direction
- Increase visibility of AAC
- Improve legitimacy of mission of ISAAC
- Become an organized political voice
  - Local, national, international
- And more….

About Supported Leadership?

2 Major Components

Training
- Individual with Disabilities
- Support Person
- Other Board or Decision-makers

Individual Supports
- Individual with Disabilities
- Board or Committee Members

What is Supported Leadership?

Promoting and encouraging people with disabilities to become active, contributing and valued members of boards and committees -
Institute on Disabilities, Temple University

Supported Leadership: Types of Training

General
- Assertiveness
- Self-determination
- Decision-making skills
- Being a good listener
- Presentation & Communication Skills
- Identifying supports you need

Specific
- How groups work
- Running a meeting
- Asking questions
- Voting
- Specific content
- Signing Documents
- Training for the Support persons and decision-makers
Supported Leadership: Individual Supports

- Personal Needs
  - Mobility, orientation, dietary, medication, hygiene, bathroom, other needs
- Transportation Needs
  - Using public transportation, arranging public transportation, paying for public transportation, other needs
- Professional Needs
  - How the group works, what I need to do, going over meeting materials, saying exactly what I want to say, staying on topic, reminders, making phone calls, putting materials in other formats, reading materials, taking notes, explaining hard words, other needs

Supported Leadership: The Support Person

- Questions to the individual with disability?
  - What will be my duties as your support person?
  - Do I need any specific training and who will do it?
  - How many hours each month will I support you?
  - Will I get paid and by whom?
  - What do I need to know about the group and members?
- Questions to ask myself
  - Am I willing to work with a person who has a disability?
  - Can I really let the person speak for his/herself?
  - Am I able to accept the commitment to be a support person? Do I have the time?

Supported Leadership: ISAAC Board or Committee Leadership

- Questions to ask/discuss with the PWUAAC?
  - What will be the duties as a board/committee member?
  - Specific training needed and who will do it?
  - How many hours each week or month will it take?
  - What do I need to know about the group and members?
  - What accommodations will you need?
- Questions each ISAAC Board/Committee Chair must ask of themselves
  - How might the person who has a disability contribute to ISAAC?
  - Can I really let the person speak for himself/herself?
  - Am I able to accept the commitment to provide needed accommodations and supports?

Supported Leadership: Some Resources

1 Source: Gobel, S. Not Another Board Meeting! Guides to building inclusive decision-making groups.

“We must become the change we want to see.”
Gandhi (1869-1948)

- Identify 1 thing that you can personally do to implement Gandhi’s call as it relates to supporting the leadership of individuals who have intellectual and developmental disabilities.

For more information or to receive a copy of this presentation, contact us at:
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