

Leadership in ISAAC: Leading the Way

Diane Nelson Bryen, USA

Sarah Lever, USA

Sayomdeb Mujherjee, India

Martin Pistorius, South Africa

Melinda Smith, Australia





Leading the Way



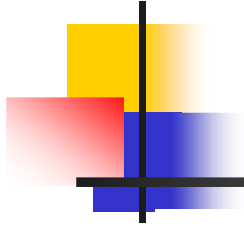
- Powerful conference title
- Important call for leadership development





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

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are needed to see this picture.

**Todo con nosotros, nada sin
nostros**

Niks oor my, sonder my

Azikhho izinto ngaphandle kwetho.



Concept of Disability: Old Paradigm Impairment--> medical/rehabilitation

- ***Location of Problem:*** within individual
- ***Solution:*** fix or cure individual; prevent
- ***Through:*** treatment/professional intervention
- ***Role:*** patient or client
- ***Desired Outcomes:*** Maximum self-care; independence
- ***Research:*** Find the best treatment to “fix” or “cure”
- ***Who Controls:*** Professionals



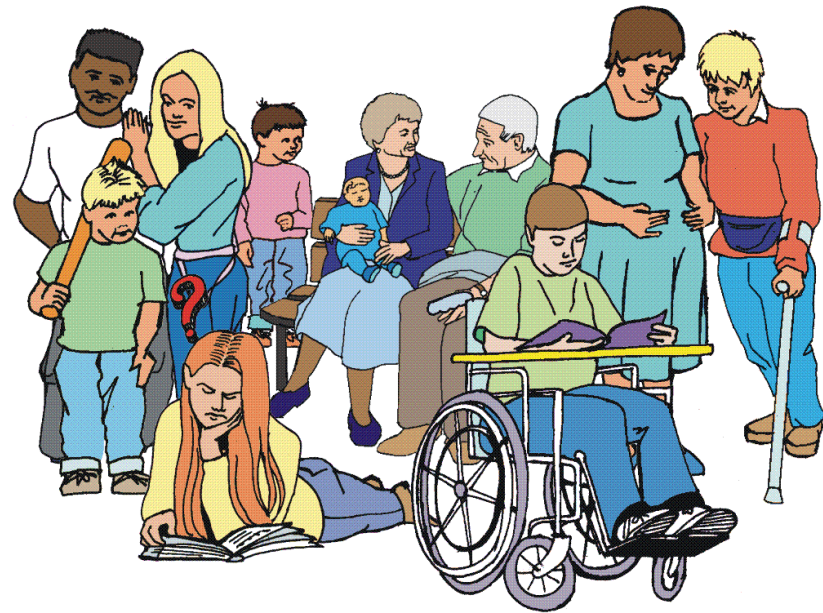
Forces have Moved Us to a New Paradigm of Disability

- **Disability Rights**
- **Human Rights**
- **Parent Movements**
- **Changes in Laws**
- **Redefinition of Disability**
- **Globalization**

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Forces have Moved Us to a New Paradigm of Disability

**United Nations
Convention on
the Rights of
People with
Disabilities**



..... Becomes International Law



Forces that Moved Us to a New Paradigm of Disability Sought to:

- End discrimination, institutionalization
- End exclusion and segregation
- Improve access
- Equalize opportunity
- Shift power
- Recognize disability as a natural part of..

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Disability is a

Natural part of the human experience that does not diminish the right of individuals with a disability to enjoy the opportunity to live independently, enjoy self determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.

Developmental Disabilities Assistance & Bill of rights Act Amendments



Disability Rights Movement demonstrated that:

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



Concept of Disability: New Paradigm Diversity, Access, Civil Rights

- ***Location of Problem:*** in the environment
- ***Solution:*** fix environment; fix social ideas
- ***Through:*** barrier removal; advocacy; consumer empowerment, choice & control
- ***Role:*** consumer/user of services
- ***Desired Outcomes:*** Choice, control, citizenship, inclusion
- ***Research:*** factors of enablement v. disablement
- ***Who Controls:*** consumer/citizen/person with a disability



Expanding the Concept of Diversity and Culture

- **People with disability -- Disability Culture; Deaf Culture; AAC Culture**
 - History, art, images, literature, political movements
- **Society to view disability as other minority cultures**
 - Discrimination, access, poverty, education and power; affirmative action, employment, hate crimes, decision-making

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 R
- ***Leadership!!!!***





International Law: UN Convention RPD

- *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

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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.”**

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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

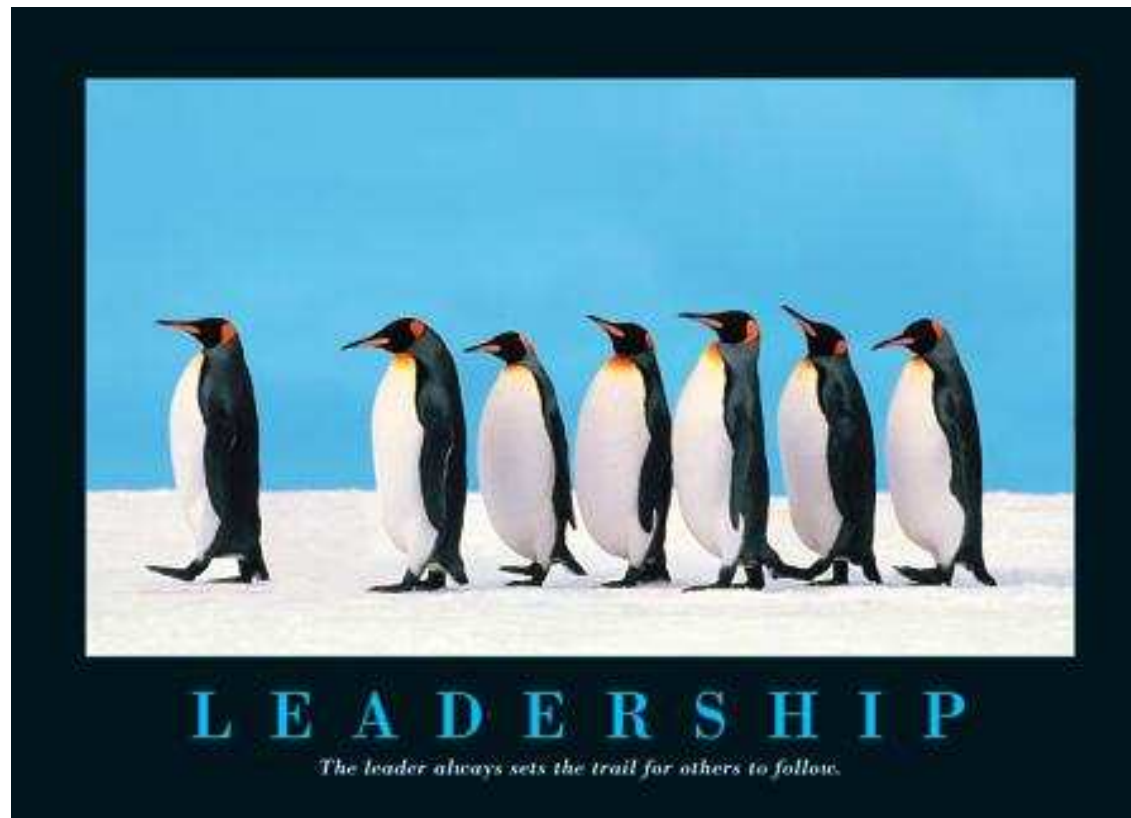
- **Article 29 -- *Participation* in political and public life**
 - “States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others...
 - (b) Promote actively an environment in which persons with disabilities can *effectively and fully participate* in the conduct of public affairs...”



What IS a Leader????

What IS Leadership???

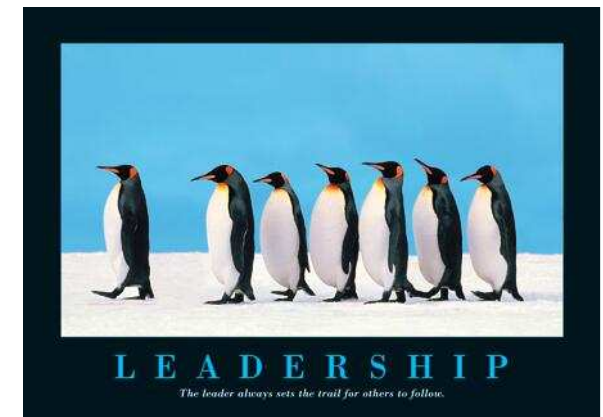
- Different definitions





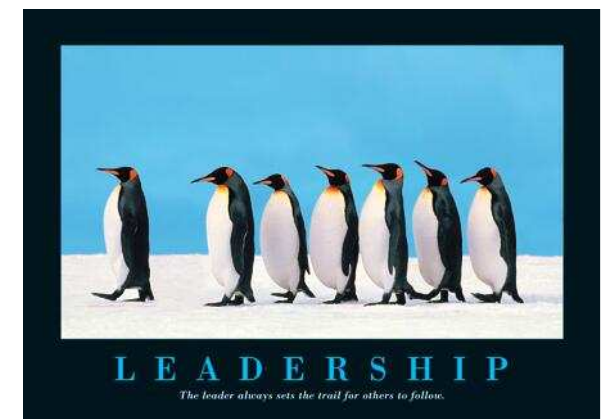
A Leader is.....

- 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.**





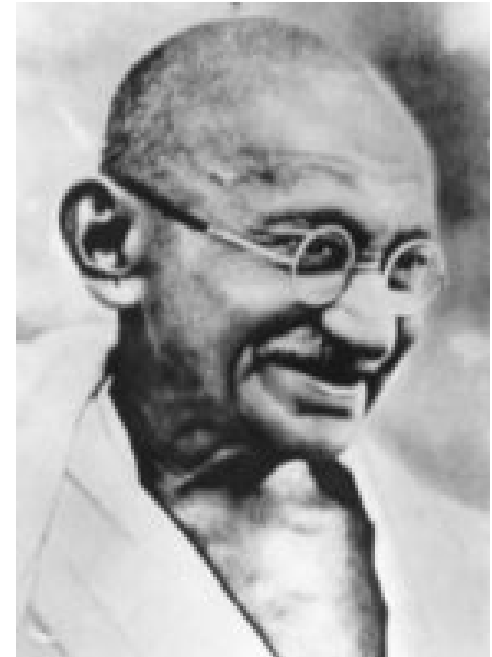
Who is this Leader?





Mahatma Gandhi

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



Who is this Leader?





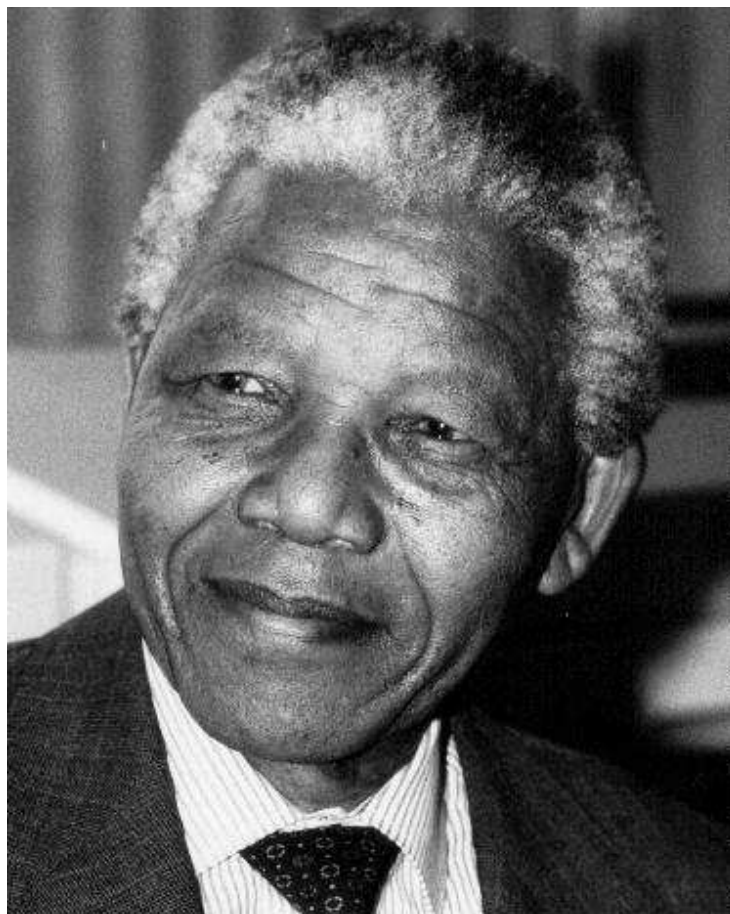
Golda Meier

She was a Prime Minister of Israel and had to lead the people of Israel through a very difficult war.





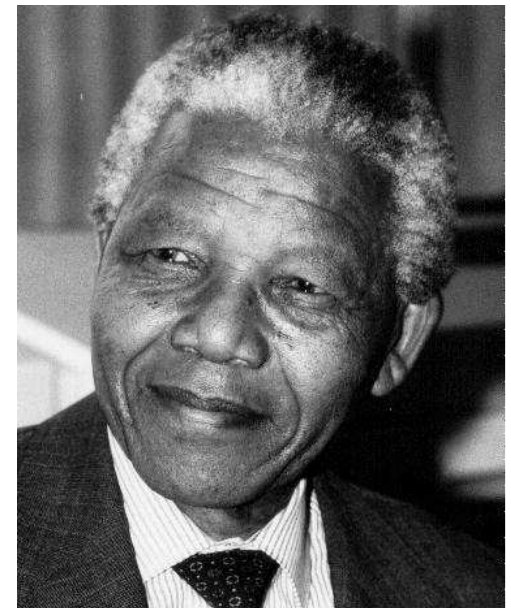
Who is this Leader?





Nelson Mandela

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



Who is this Leader?



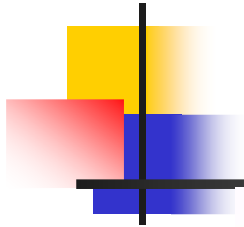


Justin Dart

He was instrumental
in the writing and
the passage of the
Americans with
Disabilities Act.



Do You Know who this Leader Is?





Meredith Allen

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



Who is this Leader?



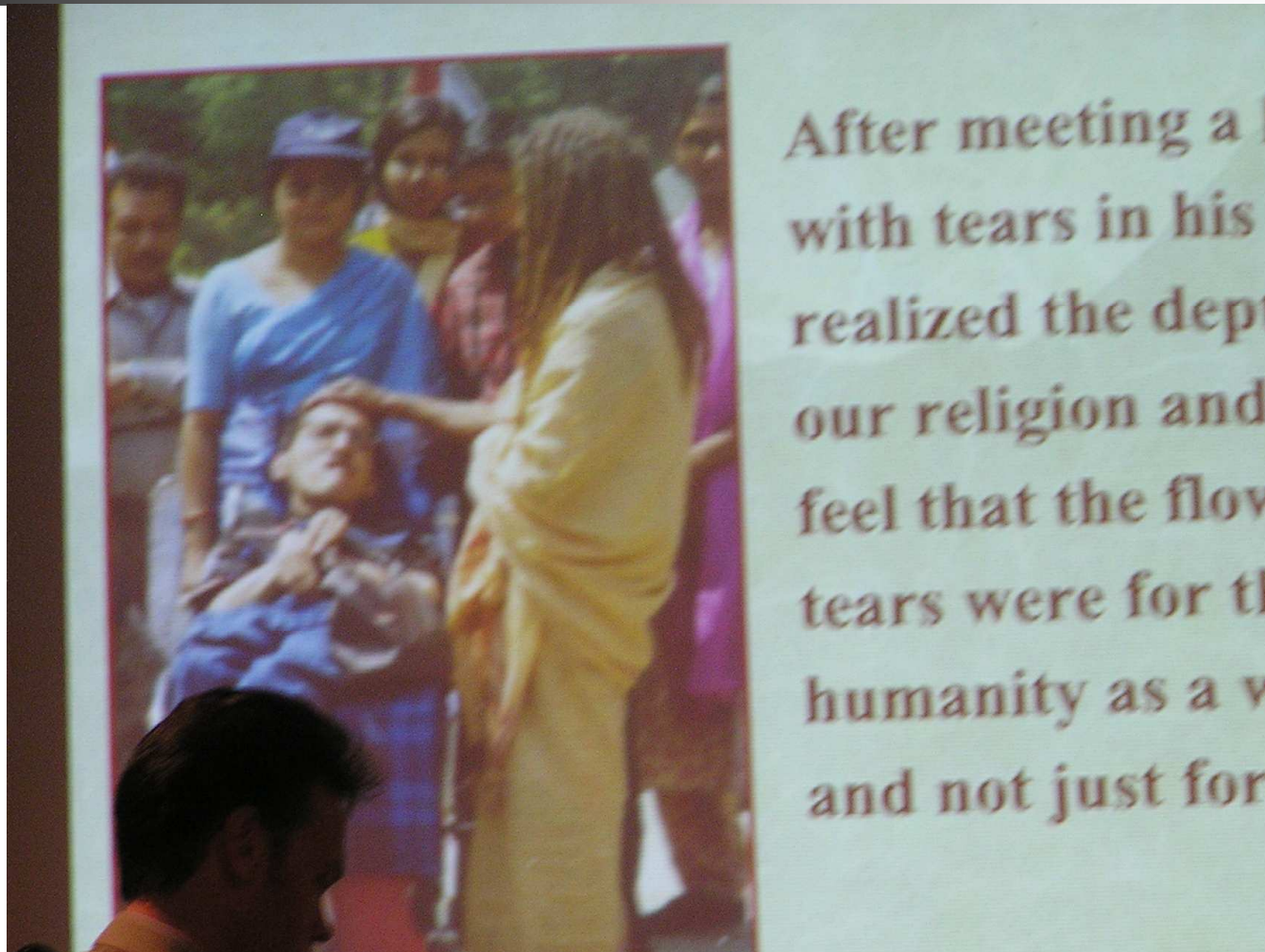


Michael Williams

Michael is the “granddad” of AAC in the US, the editor of *Alternatively Speaking*, and a partner in the RERC.



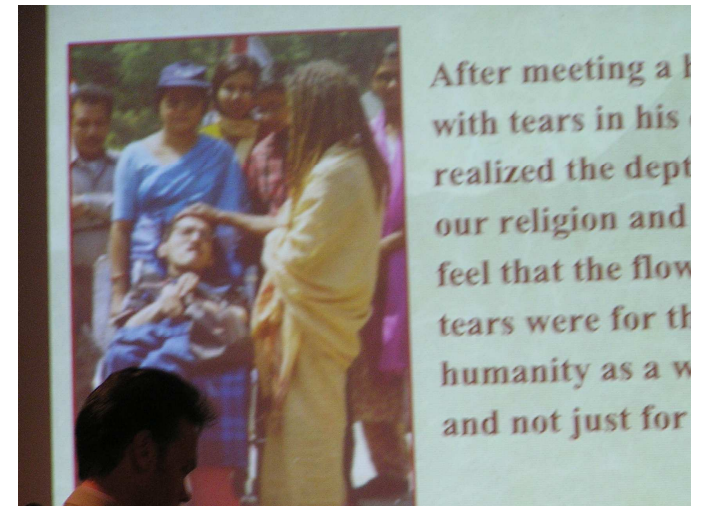
Who is this Emerging Leader?



After meeting a man
with tears in his eyes,
she realized the depth of
our religion and
felt that the flow of
tears were for the sake of
humanity as a whole
and not just for

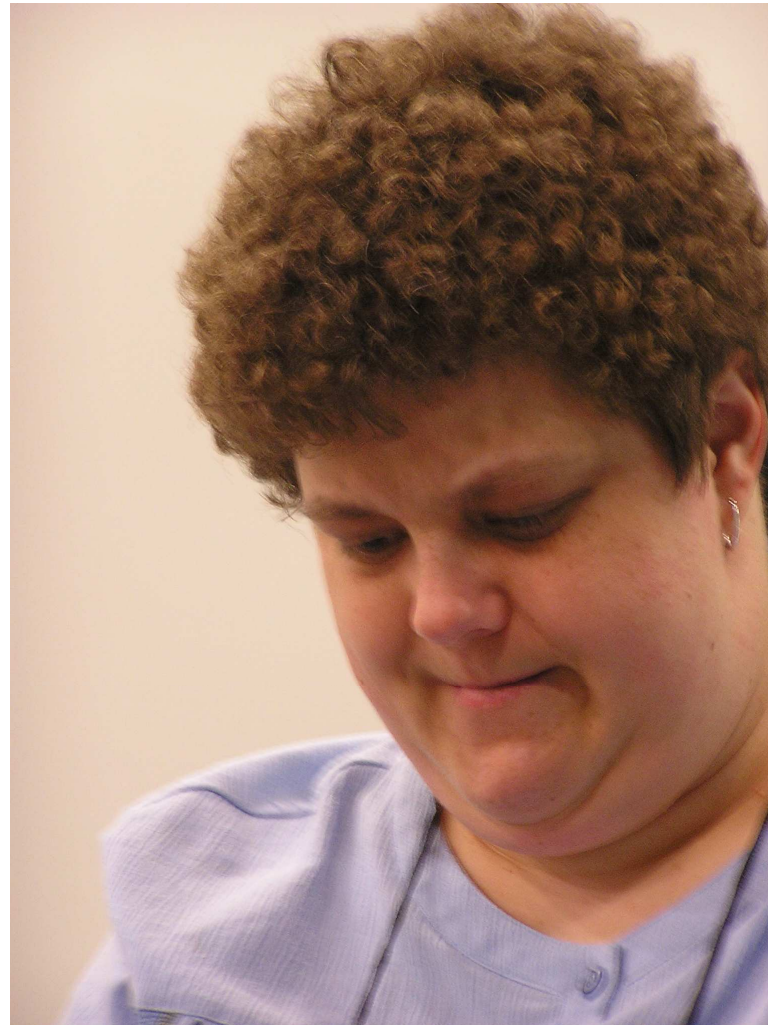
Sayomdeb Mujherjee

- Sayomdeb is an emerging leader from the Indian Institute on Cerebral Palsy in Kolkata, India. Den is a former recipient of the Words+ Award, has climbed the Himalayas, and is a participant in ISAAC's *Project LEAD*.





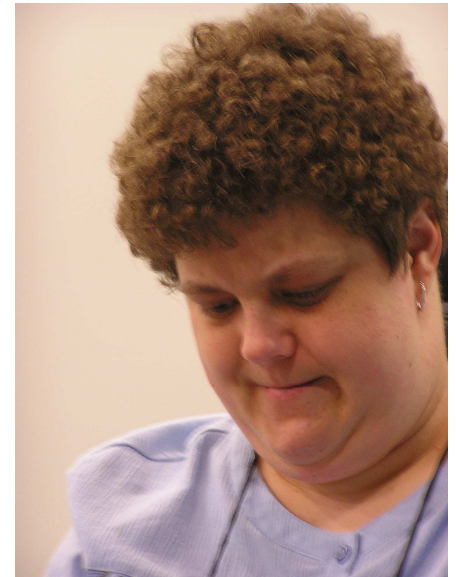
Who is this Emerging Leader?





Sarah Lever

From North Carolina, Sarah is an advocate, a co-researcher, an author, a member of ISAAC's Executive Committee, and a participant in *Project LEAD*.



Who is this Emerging Leader?





Martin Pistorious

From South Africa, Martin is a member of ISAAC's *Project Lead*. He has also been an instructor in FOFA.



Who is this Emerging Leader?



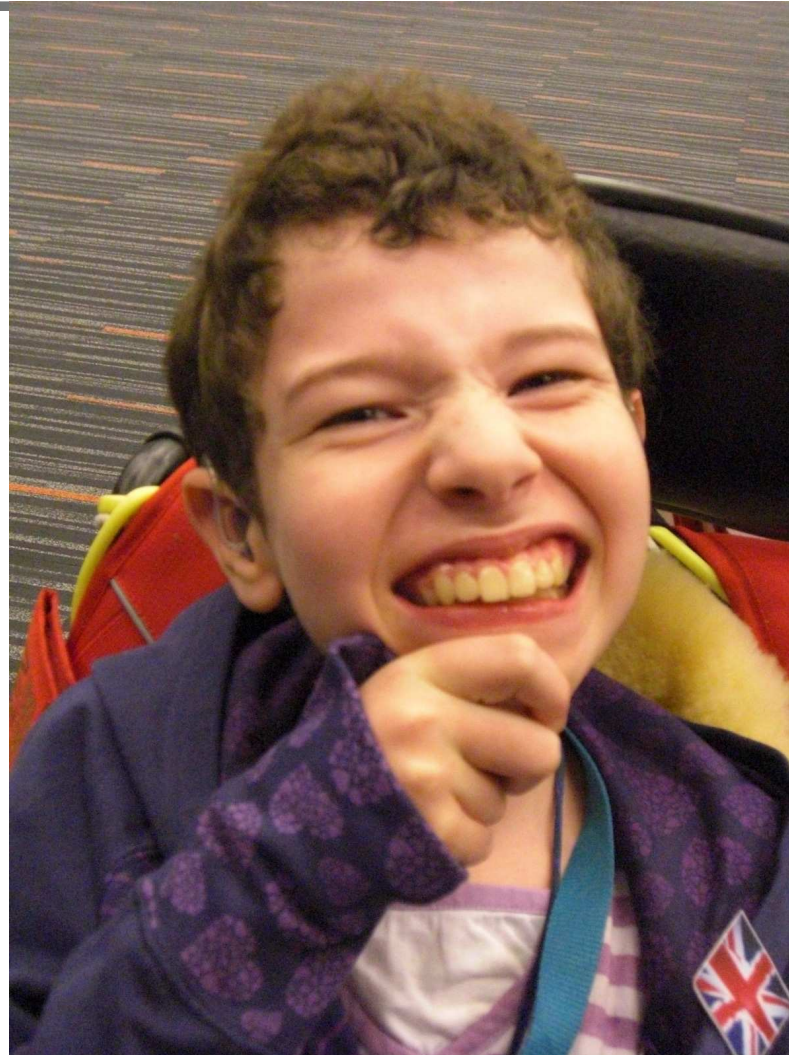
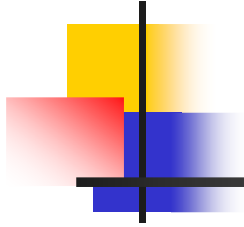


Melinda Smith

From Australia, Mel has participated in leadership programs, including ISAAC's *Project Lead*. She is one of the founders of Out of the Box with Technology and recipient of ACES' Free Speech Now Award.



Finally, who is this future leader?





Beth Moulam

From England, Beth is a 14 year old who already has the makings of a leader. Her voice is bold, her spirit bright, and she already has inspired many of us. She is the future of ISAAC.





Panel of Emerging Leaders

■ Panelists

- **Den Mujherjee, Kolkatta, India**
(could not join us at ISAAC this year)
- **Sarah Lever, North Carolina, USA**
- **Martin Pistorious, Pretoria, SA**
- **Melinda Smith, Melbourne, Australia**
- **Beth Moulam, England**



5 Questions about Leadership

1. Are people “born” to be leaders or are leaders “made”?
2. Is the development of leadership skills important for people who use AAC?
3. What and how are leadership skills developed by students who use AAC in the early years? In school? As adults?



5 Questions about Leadership

(continued)

4. **How can ISAAC's Project LEAD and ISAAC's membership support the development of leadership skills among people who use AAC?**
5. **Why is it important for the future of ISAAC to have individuals who use AAC become effective leaders?**



Question 1: Are people “born” to be leaders or are leaders “made”?

Melinda Smith: I prefer to see myself as a communicator first. A leader second. Why? Because, I am still learning about ways to be a leader. I have developed my leadership role, from my determination to be a communicator. My inspiration to be a communicator has come from my early years as a poet. As my speech was too difficult for most people to understand, I desperately needed to find a way to communicate, and through my poetry, my communication skills developed as with my emotional and personal expression skills. My AAC device back then, was solely depended on the typewriter and it became a natural thing for me to want to type words down the page, rather than across the page. Learning to communicate with myself down the page, gave me the opportunity to capture my emotions in short word burst.

Sarah Lever: You aren't born as a leader. Nelson Mandela, Gandhi might be born with the knowledge to be leaders from somewhere inside them but, most of the people have to learn how to be leaders. In America, we have the Girl and Boy Scouts to get children and teenagers ready for leadership roles. Normally, Boy and Girl Scouts are for "children and teenagers with no apparent disabilities" and they teach the children how to be leaders. But, how do children with disabilities learn how to lead a group of people? In fact, they don't. It is a deep lack of opportunities for AAC users to learn how to lead a group or meeting. That is sad because children with disabilities need to learn how to lead a group. I was lucky my mom got me into girl scouts at an early age.



Question 1: Are people “born” to be leaders or are leaders “made”? (cont.)

•**Sarah Lever:** You aren't born as a leader. Nelson Mandela, Gandhi might be born with the knowledge to be leaders from somewhere inside them but, most of the people have to learn how to be leaders. In America, we have the Girl and Boy Scouts to get children and teenagers ready for leadership roles. Normally, Boy and Girl Scouts are for "children and teenagers with no apparent disabilities" and they teach the children how to be leaders. But, how do children with disabilities learn how to lead a group of people? In fact, they don't. It is a deep lack of opportunities for AAC users to learn how to lead a group or meeting. That is sad because children with disabilities need to learn how to lead a group. I was lucky my mom got me into girl scouts at an early age.

Martin Pistorious: That question is a bit like which came first, the chicken or the egg? I think it is a bit of both. I think there are those individuals who have a natural predisposition to be a leader and are readily followed by others. They are then shaped by life experiences, their circumstances and possibly mentorship and formal leadership training to be a leader. Obviously, just as everyone can and does communicate, some people are better communicators than others. So too is it with leaders, some are truly gifted leaders like Nelson Mandela, others need to make more of a conscious and concerted effort to be a leader. Like some people learn to play music and others can just do it, yet both of them are musicians.



Question 2: Is the development of leadership skills important for people who use AAC?

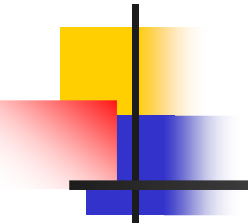
Melinda: Yes it is, but people need to work on their personal skills first, to develop confidence, and communication skills. Over the years, I have used poetry as a way to empower my voice, and to learn about what I am thinking and feeling. Doing this has also matured my mind, and broadened my experience of communicating with the outside world. In my early years of voluntary work and employment as a freelance writer and presenter, I was put into situations that totally intimidated me, and I had two choices, sink or start swimming. I began swimming. I wanted to work on my confidence, and my communication skills, particularly from the perspective of an AAC user. People did not naturally believe I could do things, and I had to find ways to lead the way, and being aware of my own communication skills, was a big part of the learning process.

Sarah: Yes, development of leadership skills are very important for people who use AAC because we have to be the leaders in our personal care. For an example, we have to tell people who are helping us how to do everything.



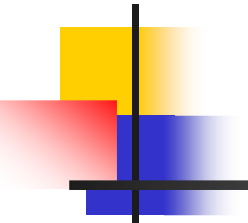
Question 2: Is the development of leadership skills important for people who use AAC? (cont.)

Martin: Yes! I believe it is fundamental for people who use AAC to develop leadership skills, irrespective of whether or not they take up a formal leadership position. The skills, self confidence and assertiveness that an individual gains through the development of leadership skills will play a significant role in ensuring the person lives a self determined life. You become the leader of your life. It is also critical that when a person who uses AAC finds themselves in a leadership position either through their own initiative, or an opportunity presented to them they have the skills to thrive and make a real impact.



Question 3: What and how are leadership skills developed by people who use AAC in the early years? In school? As adults?

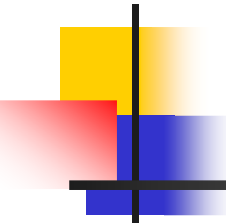
Melinda: Joining committees and taking up further studies has developed my skills, to put the process into practice around real people in real time. The same with employment and being able to be involved in projects, where particular leadership skills are required. I also took up the role of chapter president for ISAAC, which again threw me in the deep end. Although it was a great experience of learning the role of being president, I struggled with the role of management and being assertive in decision making. It was very much something I learned more about as time went on. I can remember my first ISAAC board meeting in Brazil and I simply had very little to say, because I did not know my role enough and again, it intimidated me. I also participated in a Leadership training course for a year. That had a huge impact on building my knowledge and listening skills, as well as being able to assert myself better in meetings and have more confidence to take on new projects in my workplace.



Question 3: What and how are leadership skills developed by people who use AAC in the early years? In school? As adults? (cont.)

Sarah: By learning how to share when children are little that is the beginnings to learning the leadership skills. In school, children join clubs and they develop leadership skills from being in groups. As adults, usually we are on one or two committees at once. We learn how committees work and usually we are the leaders sometime in our lives once.

Martin: This is one area where I feel people who use AAC generally speaking are currently disadvantaged. I think the leadership skills are mostly developed as adults because young people who use AAC don't have as many and in some cases any opportunities to be in a leadership role while they are growing up. This is due to the time it takes to communicate and people taking decisions for and on behalf of the person who uses AAC. Therefore I think often people who use AAC have very limited opportunities to develop their natural leadership abilities. I think this is why most people who use AAC only develop leadership skills as young and even not so young adults; when they move into being more self determined.



Question 4: How can Project Lead and ISAAC's membership support the development of leadership skills among people who use AAC?

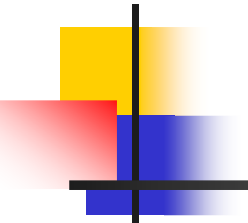
Melinda: What I think is exciting about the leadership project within ISAAC, is the opportunity for consistency and greater awareness on a global level. It would be great to see the same leadership guidelines being used by ISAAC in all countries. ISAAC can also expand on the opportunities for individuals to experience, and actively engage in leadership roles. We do however need to define clearly what a mentor is. Make the development skills learning fun and interesting, rewarding and educational because not every AAC user wants to become a leader, some may simply want to communicate better with a group of friends around the table. It should not a therapy session, and should open to any non AAC user, who is interested to enhance communication partnership.



Question 4: How can Project Lead and ISAAC's membership support the development of leadership skills among people who use AAC?(cont.)

Sarah: A good leadership program is needed by each great organization to teach the younger members to be good leaders when they are the organization leaders. ISAAC needs to support the LEAD project because developing leadership skills are so important.

Martin: I believe ISAAC's Project Lead can promote and facilitate the development of leadership skills by reducing barriers, creating a supportive environment and opportunities that are conducive to leadership. I think a two pronged approach is needed. The first is to facilitate the development of leadership skills for people who use AAC, by things such as leadership and mentorship programs beginning at school level, including having mentorship and intern programs where people who use AAC can get "hands on" experience. Then lastly, formal leadership training which would look at several aspects of being a leader, such as improving self confidence, assertiveness, conflict resolution, decision making and so on. The second aspect is an awareness and educational initiative where temporarily able bodied people otherwise known as normal people are educated and sensitized to the accommodations needed by people who use AAC, and AAC etiquette.



Question 5: . Why is it important for the future of ISAAC to have individuals who use AAC who are effective leaders?

Melinda: It would be a great achievement to have more AAC users leading the direction for ISAAC. It would allow AAC users to demonstrate empowerment, using their voices. At the moment there are not a lot of AAC users leading the way. If ISAAC can manage to get it right, then it will be leading by a good example.

Sarah: The LEAD project is going to give us as the future of AAC a framework to learn how to become good leaders. It is like parents show their children how to do things before they let the children to do something. The future of ISAAC lays within the AAC users because the ISAAC wishes to have an AAC user as president.



Question 5: How can Project Lead and ISAAC's membership support the development of leadership skills among people who use AAC?(cont.)

Martin: It is not important, it is absolutely crucial, that there are people who have the leadership skills to carry, lead and develop ISAAC into the future. As the saying goes, “nothing about us, without us”.. If people who use AAC are not part of the ISAAC leadership, and do not fulfill key leadership positions, the organization is in danger of losing touch with its true purpose. ISAAC, as I understand it, has Special Consultative Status with the Economic and Social Council of the United Nations. I personally would not want someone who is not a person who uses AAC to be talking to the United Nations on our behalf. An AAC user should at least be part of the delegation that the United Nations consults with.

Beth Moulam: I am just like everyone use but I use AAC. It is important for people to see past my disability and that of other AAC users so we can speak out for ourselves. Everyone needs role models at whatever age they are so a young child who gets a communicator needs someone like me to show them the way. Someone with a voice needs someone who uses AAC to explain what it is like to have no voice.



Promising Leadership Development Programs

- Center for Creative Institute, 2008;
- Disney Institute, 2008;
- Harvard Business School Leadership Initiative, 2008;
- Partners in Policymaking
- Youth Leadership Network
- Self Advocates Leadership Program-Temple U, 2008
- **ISAAC's Project LEAD**

All have the following in common:

- Vision building
- Skills building
- Mentoring and practice
- Opportunity (moving aside and the shift in power)

“We must become the change we want to see.”

Gandhi (1869-1948)

- Finally, the leadership and the membership of ISAAC must listen carefully to the words of this very important leader



- Identify 1 thing that you can personally do to implement Gandhi's call as it relates to supporting the leadership development of people who use AAC.

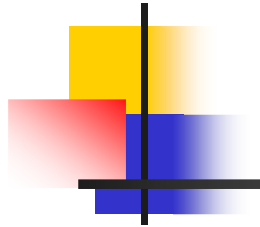
“We must become the change we want to see.”



Gandhi (1869-1948)

Here are some ISAAC members' responses. I will....

- **France -- I will translate this into French for the ISAAC website**
- **Australia – I will support 4 individuals to develop leadership**
- **South Africa- I will continue FOFA in SA**
- **SLP – define leader and ask adults what they can do**
- **Toronto, Canada – I will facilitate mentorships**
- **Jen Lowe/USA – I will continue speaking out and speaking up**
- **Finland – I will inform all countries – web pages; translate into Finish and Swedish**
- **Leigh Ann Lightholder/USA – I will mentor AAC users who are not using their devices at UCP in Pittsburgh**
- **Libby/Australia – I will bring someone who uses AAC to Barcelona**
- **Kitty/South Africa -- I will bring a FOFA student to Barcelona and I will nominate someone like Martin to be on the ISAAC board.**



Thank you
Danke Xie xie
Khawp khun
Gum ǒǒǒ
Salamat Mahalo
Juspañña
Spacibo Obrigada
Arigato