



AAC – a communication alternative or the language of apartheid.

A Sociological Discussion Paper

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2011

Conner — 22yrs, successfully completed HSC last year, cerebral palsy with CCN.

Arrives at the Royal Adelaide Hospital ED accompanied by his Father and a carer.

After questioning Conner's Father and his carer about Conner's history, condition the registrar decides he "has not come to terms with his disability" and should be reviewed by a Psychiatrist for depression.

Conner's Father has left his communication device on the back seat of the car. Experience has taught him that staff in ED rarely have/take time to enable Conner to use it.



Conner

- **Known**

- Conner's Mother and primary care-giver died 3 months ago.
- His case worker, father and carer have been unsuccessful in locating counselling and group support for Conner. The local community health service offers interpreter services but does not feel they can confidently meet the counselling and group work needs of Conner.
- Conner's communication device is somewhat unreliable and is on a waiting list for review.

- **Unrecognised facts**

- Conner has no face-to-face peer/social contacts.
- After meeting the solitary Campus Disability Advisor last year, he was unable to accept the University offer he received due to the gaps in campus support (environmental, care, technology/AAC).
- In the last state election Conner and his carer had attempted to vote at the Poll Booth – but he was turned away (carer presence and voice-output of device). “You need to use your own voting system” he was told.

Why apartheid?

Apartheid as a social policy has been universally condemned. However, an analysis of policy and practice in the field of disability shows many disturbing parallels with apartheid.

Jackson & Cowan (1994)

INDICATORS: **EXCLUSION** **SEPARATION** **SEGREGATION**

- The treatment of people with disability varies to policy and rhetoric of inclusion and integration.
- The physical environment of services and grouping 'segregation' of people e.g. housing, Paralympics etc.
- Language indicates a systemic segregation of people. This includes deficit language but also the segregation of language e.g. AAC not recognised as a functional language within mainstream society and indeed, much of the disability and health sectors e.g. Consumer Rights and Responsibility documents.

DISABILITY

IN AUSTRALIA

EXPOSING A SOCIAL
APARTHEID



GERARD GOGGIN & CHRISTOPHER NEWELL

AAC as Apartheid

- AAC Language barriers are so profound they are precluded from the most basic of social safety nets.

e.g. Ryan

What protects his rights to communicate for himself at the hospital?

What protects his rights to privacy (persons speaking for him)?

How does Ryan access basic primary health services such as counselling and group work?

What ensures his right to access a university education which is supported by teaching staff that are required by law to be trained in the use of his communication device?

What protects his right to use his communication device in public?



United Nations

United Nations A/61/61 | **Sixty-first session** Item 67 (b)

Promotion and protection of human rights: *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* General Assembly

6 December 2006

Article 2

Definitions

For the purposes of the present Convention:

“Communication” includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

“Language” includes spoken and signed languages and other forms of non-spoken languages;

World Health: ICF International Classification of Functioning

When announcing the ICF Framework at the 2002 WHO Conference Trieste, Opening Speech, the Director General of WHO states –

“More than anything, the ICF is based on the value of inclusion, and on a universal model of disability. It rejects the view that disability is a defining feature of a separate minority group of people.”

Yet then states –

“Only healthy people with the support of a functioning health sector can ensure sustainable development of their societies. A loss of health is a loss not only to the person but also to the person’s family and society as a whole.”

Reproducing old, enduring, disablist views of disability – p.57 Goggin & Newell (2005)

Right 2.2: Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity.

Please consider:

1. Does the case history/medical record have a specific section for recording children's comments or complaints about treatment?
2. Do healthcare professionals seek the views of children and young people regarding their condition, treatment and other relevant issues? And do they take them into consideration?
3. Do healthcare professionals discuss children's condition, treatment and other issues with parents, guardians and caregivers? Do they discuss separately with children and adolescents, if it is in their best interest?
4. Are there means for seeking the views of children and their parents in foreign languages, for instance through language mediators?
5. There is a Forum for child/young people or parent/child. The forum is supported by hospital authorities.
6. There is a mechanism to record patients' experience.
7. Are there family and child friendly complaints procedures or reference units, staff and/or volunteers for children and adolescents to express their complaints? And are these accessible to all children and young people?
8. Have there been any complaints by children, parents or patients' associations about the denial of this right in the past 12 months?
9. The hospital has received praise from children and families. There have been positive media stories regarding the hospital's respect for this right.

Please highlight what you believe is missing in relation to the respect of this right, record evidence of how policies are applied in the hospital or the right is met and record useful proposals for the definition of standards on the respect of children's rights in hospital.

Were there diverging opinions among members of the evaluation team? (please give examples)

AAC???

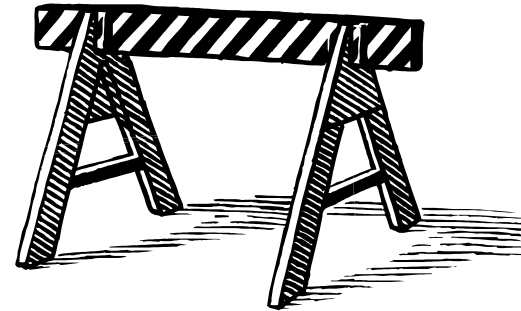
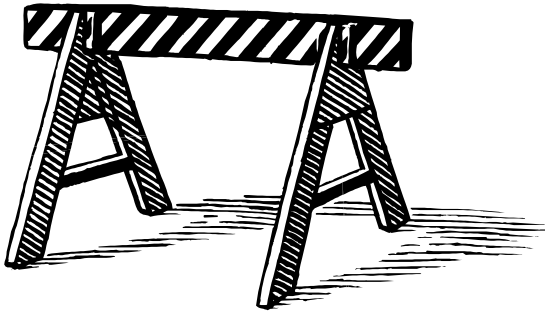


SO.....WHAT'S THE PROBLEM?

Policy

Advocacy/Planning/Action

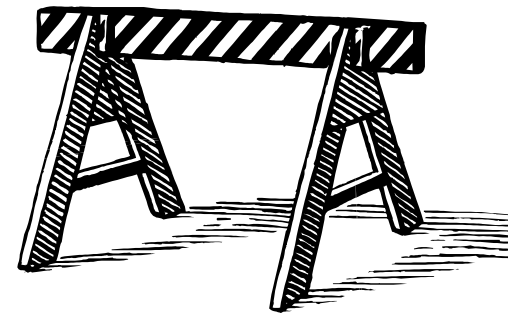
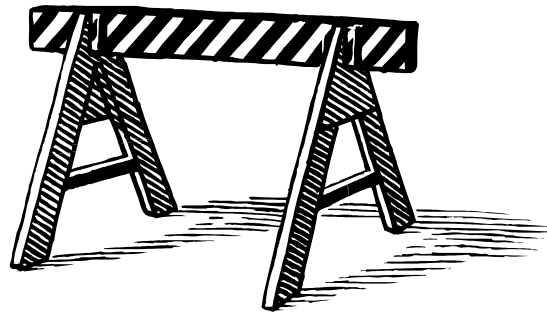
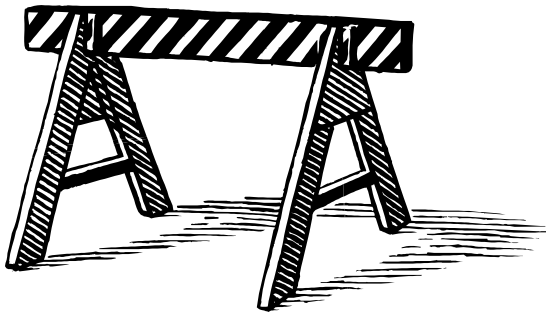
Service Delivery Models



Community Awareness

Legislation

Resourcing



Do the structures of Australian service provision challenge apartheid?

Services are very rare that refuse to segregate and congregate people with a disability.

Jackson R (1994)

Bill Shorten described current disability services as a 'major human rights issue' with people with disabilities forced to live 'a second class existence'.

Media Release: Public Meeting June 30 / 2010
Adelaide Town Hall.

1. Are people with disabilities passive recipients of services?
2. To what extent is 'consumer' leadership promoted within services?
3. Do services encourage client self-determination, self-advocacy, citizenship, group empowerment, legal rights and service leadership?

Rights and Legislation

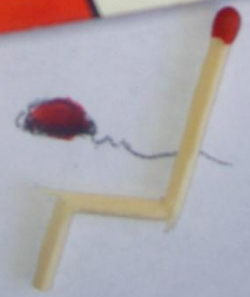
- Anne McDonald proposed the establishment of **"a right to communicate in formal situations such as courts, hospitals and schools"** because **"Without such legally enforceable rights, people without speech will be at the mercy of decision-makers who can arbitrarily refuse to disallow communication."**



**ENJOY
CITIZENSHIP**



If you can speak my language



Citizenship

To ensure full citizenship, people must be empowered to participate in the continual processes of shaping their society, their communities and their identities. Kenny (1999)



Participatory communication includes –

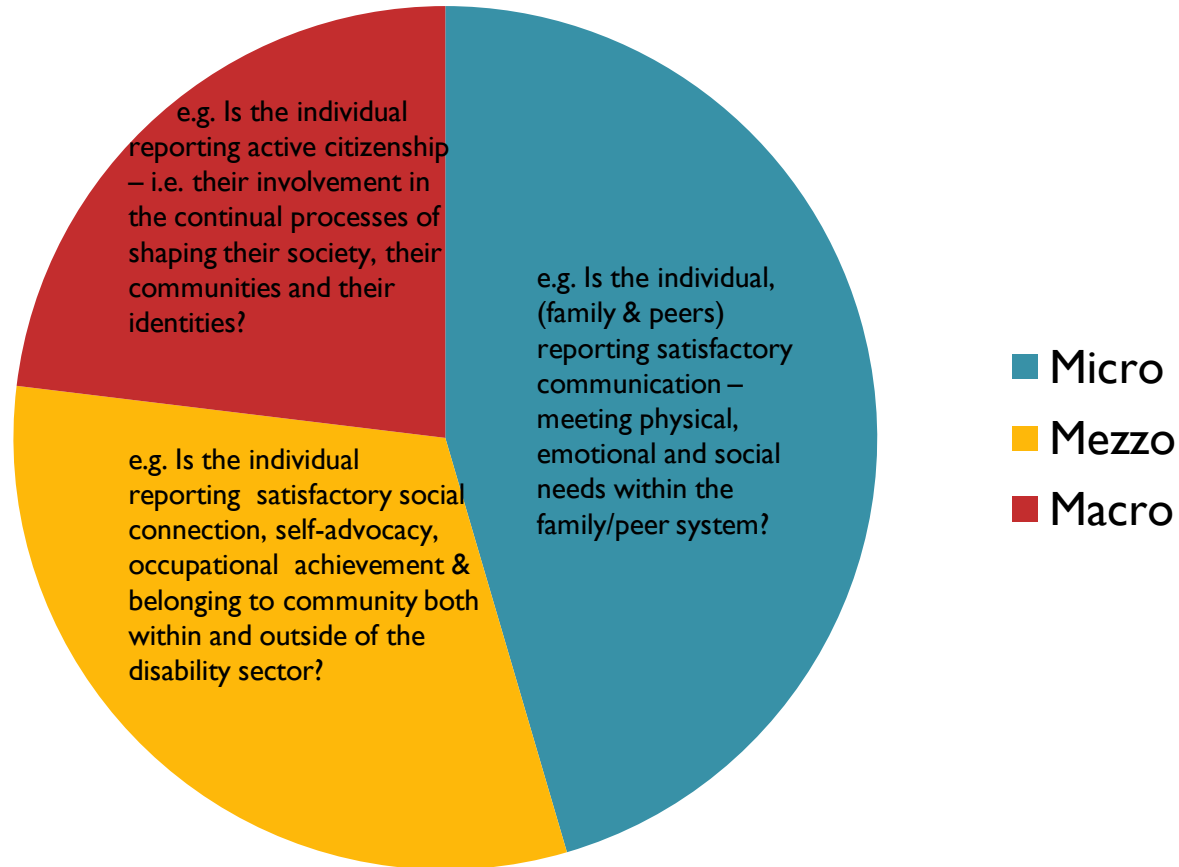
- Public Speaking
- Community development
- Meetings, Committees
- Forums
- Planning e.g. AGOSCI Conferences
- Voting
- Media pathways
- Lobbying
- Awareness raising
- Community leadership



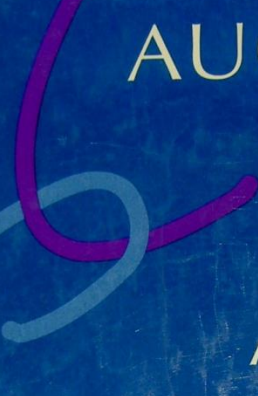
Communication
Rights
Ahead

AAC tested

Participation Assessment



David R. Beukelman & Pat Mirenda



**AUGMENTATIVE
and
ALTERNATIVE
COMMUNICATION**

Management of
Severe Communication Disorders
in Children and Adults

Second Edition

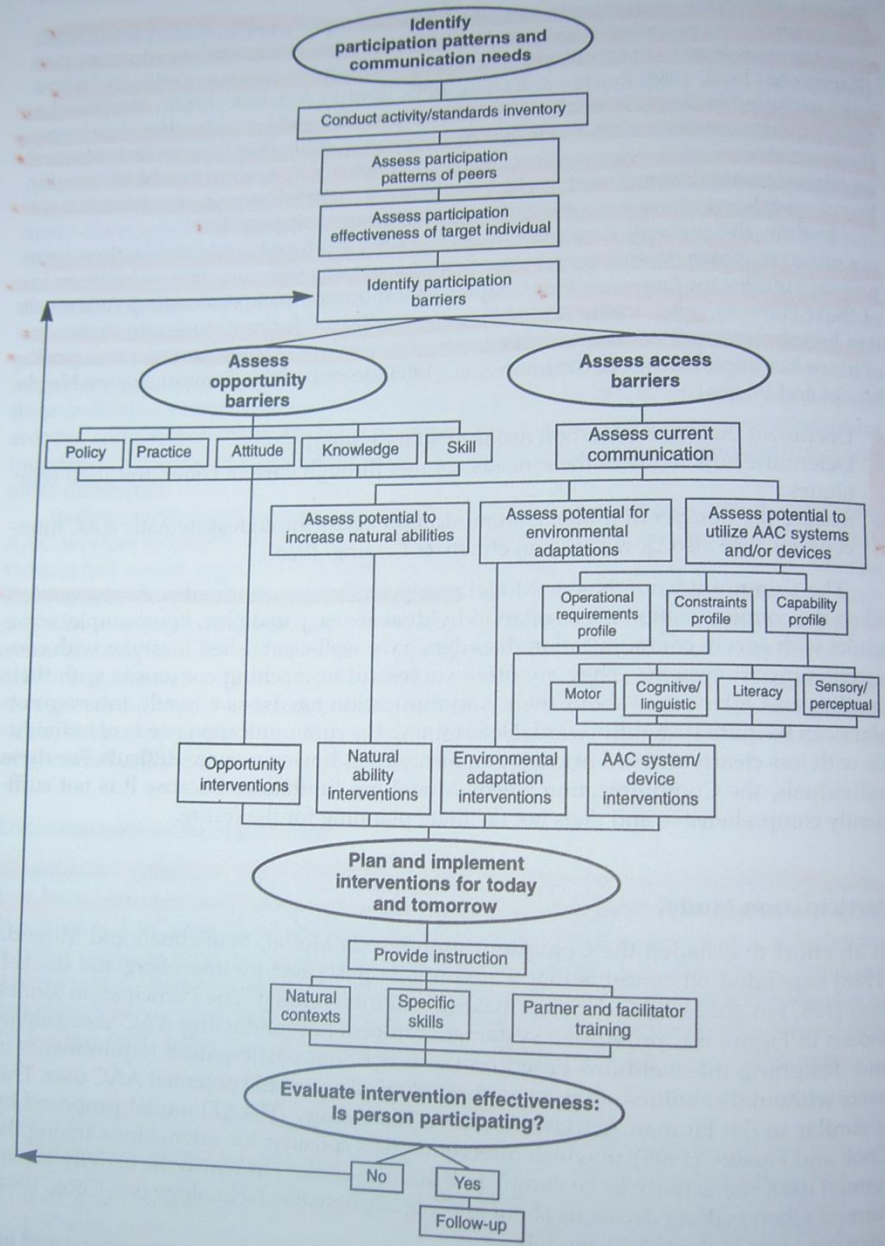


Figure 6.1. The Participation Model.

Participation Model — Beukelman D & Mirenda P

- **STRENGTHS**

Recognises barriers to participation.

Provides AAC specialists with a broad formula for participation promotion at the micro level.

- **AREAS TO EXTEND**

View of participation – micro mezzo and macro levels.

Detailed solutions.

Training and support of workforce.

Suggestions for organised advocacy.

What needs changing

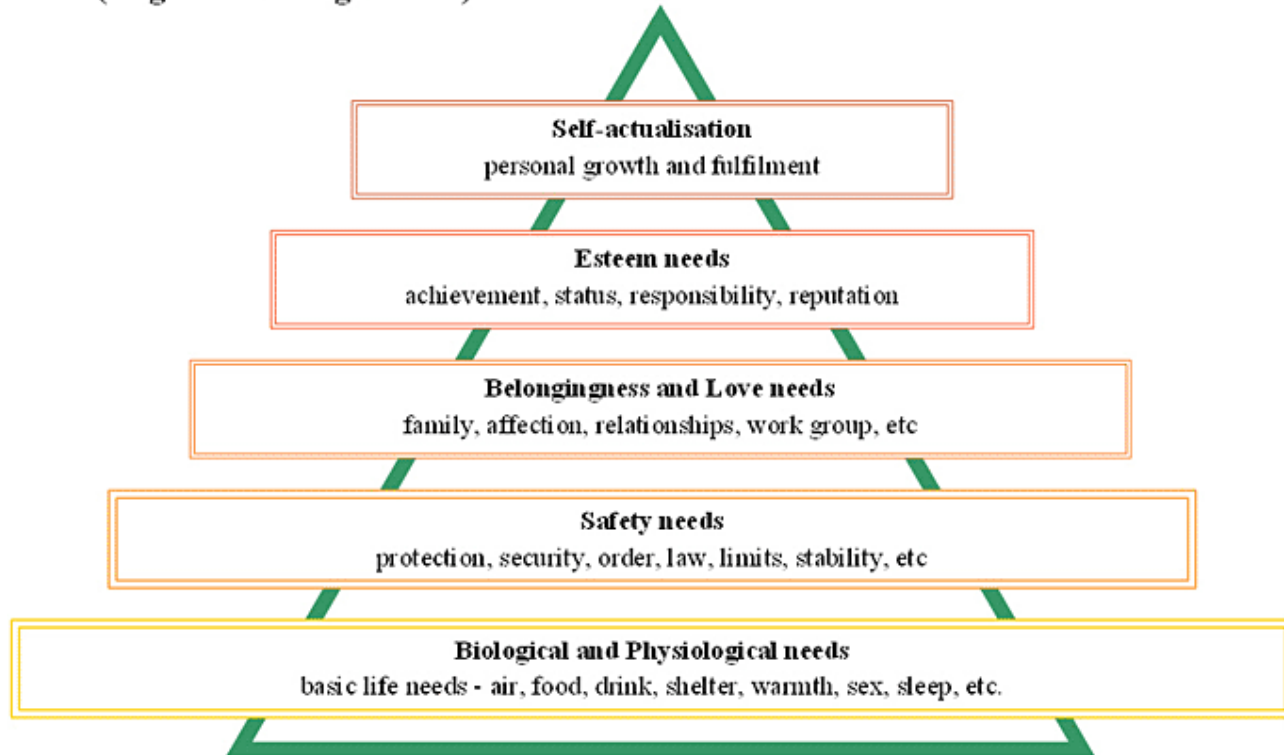
- AAC to shift from the tool-kit to the social and political platform.
- Field of AAC to re-view and reform e.g. Participation Model.
- Focus on community communication partners.
- Formulation of coalitions.
- Active promotion of client leadership and self-determination within service sector.

Macro Practice

- Aimed at improving or modifying some aspect of society.
- Advocate for and regulate resources to clients.
- Changes made to 'the system' so that clients can exercise their rights.
- Requires the practitioners good understanding of the social/political context of their work as well as the barriers and opportunities.
- Usually involves advocacy. Kirst-Ashman & Hull (2006)

In which area does AAC perform most - least well?

Maslow's Hierarchy of Needs
(original five-stage model)



© alan chapman 2001-4, based on [Maslow's Hierarchy of Needs](#)

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AGOSCI'S ROLE

What is AGOSCI?

AGOSCI is a group representing people with complex communication needs, as well as those who live, know or work with people with complex communication needs.

Established in 1981, AGOSCI aims to lobby for the rights of people with complex communication needs, increase public awareness of complex communication needs, and to provide relevant educational and professional development events across Australia.

Pie Diagram

Does AGOSCI promote the citizenship of its AAC language users?

“People must have control over knowledge and information, social relationships, decision making and their own resources”.

“Structures and processes should be developed whereby people can take collective responsibility for, and control of, the way in which their lives are organised”.

Kenny S (1999)

- Community development - borrowing from models.
- Forming task ‘action’ groups.
- Working with coalitions e.g. welfare groups.
- Lobbying.
- Petitioning.
- Working with media- preparing a media release.
- Empowering community e.g. Forming groups, Shaping AAC for Macro involvement.
- Educating –e.g.AAC workforce.
- Community awareness raising.

Some Take-Away Ideas

- AGOSCI to shape it's Advocacy role. Planning/resourcing. Peak Body? Forming of coalitions/alliances.
- AGOSCI – ISAAC to challenge apartheid – particularly at the Macro level e.g. UN, WHO
- Training for AAC providers – assessment at all levels.
- AAC tools/devices built to promote leadership, mezzo and macro communication.
- Your ideas!!!!



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