



Active Citizens Or Passive Recipients: How Australian Young People With Cerebral Palsy Define Citizenship

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What is Citizenship?

- “A person being integral to their community; a person who both is valued and respected, and feels valued and respected within their community; a person whose inherent dignity as a human being is upheld; and a person whose uniqueness is not only recognized but is also considered a valuable contribution to a rich and dynamic societal fabric” (Knox, 2006, p.3).



What is Citizenship? (cont')

- The legacy of T. H. Marshall
- Not a philosophical debate
- Focus is on participation in everyday occupation:
 - ✓ enjoying life (leisure), and
 - ✓ contributing to the social and economic fabric of their community (productivity)



Rationale of the Study

- People with disabilities (20% of population)
- More challenges during transition to adulthood
- Holistic view of ‘disability’
- Contested definition of ‘Young Adult’ & a linear trajectory of life development
- Services to young adults with CP decline after 18
- Lack of evidence on their citizenship experiences
- Most focused on children/older adults & quantitative (King, Cathers, Polgar, MacKinnon, & Havens, 2000; Overeynder & Turk, 1998; Stevenson, Pharoah, & Stevenson, 1997)



Objectives

This presentation aims to provide:

- Perceptions of citizenship from young adults with CP
- Factors that influence their opportunities to obtain citizenship experiences



Method

Design

- Naturalistic inquiry (Patton, 2002)

Purposive Sampling*

- 9 young adults with CP

Data Collection

- Semi-structured interviews

Data Analysis

- Verbatim transcription
- Inductive analysis
- analyst-constructed typologies

Inclusion Criteria:

- **Age between 18 to 30**
- **Completed year 10 of secondary school or above**
- **Living at home or independently in the community**
- **Ability to understand both verbal and written information and capacity to respond to questions during an interview**



Demographic Details

Demographic Characteristics of Participants (N= 9)

Age		Mean= 25
Gender	Male	5
	Female	4
Education level completed or currently involved in	Year 11	3
	Year 12	3
	TAFE Certificate or Diploma (or equivalent)	2
	Degree or Post Graduate Qualification	1
Living Situation	Living alone in rental accommodation	1
	Living with parents	4
	Living in own home	3
	Living with partner	1
Current activities	Not involved in paid work presently	2
	Working part- time	2
	Studying (TAFE or University)	3
	Finishing high school	1
	Carrying volunteering duties (otherwise not involved in any paid work presently)	1



Perceptions of Citizenship

Contribution: ‘Taking the responsibility’ for themselves and others, and ‘making a contribution’ to their surroundings were the major characteristics of citizenship participation

- “To be a citizen means to be loyal, community-minded, care about the community, children, the elderly and the animals.”
- “A good citizen is someone who helps other people out, instead of just thinking about themselves.”
- “They ask you about your disability and try to get to know you as a person. People often ask ‘how did you end up in the wheelchair?’ That’s probably one of the most common questions. I am quite often in that role as an educator, which I think it is a very valuable role to have. I feel like a valuable part of the society. I really do.”



Perceptions of Citizenship

Inclusion: Citizenship involved identifying with and feeling a sense of belonging to one's community

- “[Being] part of the community means participating and I am just living, living. It’s the isolation and how society looks at people with disabilities.”
- “I volunteer on a steering committee in my local council. The things you do [in the committee] do impact upon other people in the community. It’s good to see the result at the end of the day and to know your opinion is valid. You are seen as important and being respected in your community.”
- “I want to be a role model for people with a disability and say ‘Hey you can do this [taking part in the community]. If you put your mind to it, and get it right. You can do it!’”



Perceptions of Citizenship

Equal Opportunity: To be independent and have the rights and capacity to exert control over and direct their lives

- “I want to be a normal person in a normal environment, have my own house, not renting. To me renting is like paying off someone’s debt. I’d like to have my own home, my own car, a husband, and children.”
- “I don’t want financial help from them [family] because I’d feel like I’m mummy and daddy’s girl but I’m not. I just want to do something I like to do, be independent. I’ll try to do as much as I can without any help or assistance. To me, that’s being independent. If I need help, then I’ll ask.”



Perceptions of Citizenship

A barrier-free context: Society needs to create a barrier free environment for including people with disabilities to experience the reality of being full and equal citizens

- *Societal factors* included how society perceives people with disabilities in general.
- *Support factors* included having strong social support and building sustainable relationships were seen as key elements to enhance citizenship.



Perceptions of Citizenship

Societal factors

- “Stigma, the stigma that’s attached to [people with disabilities]. Some people put a label on people with disabilities and think people with disabilities are all the same and that is not true.”
- “People think we’re stupid but we are not. They think we’re not intelligent.”
- “Some people may see us as a strain on society or burden.”
- “I’d like to write a book about my life or ask other people with disability to participate in my book, talking about how they feel as a person, how people see them and write them as a book. It will give people an understanding of what we go through as individuals in the community.”



Perceptions of Citizenship

Support factors

- “I love being around people, it’s like a gift for me but [where I live] it is, isolating.”
- “I am so isolated. I don’t go out. I’ve just never got invited to many things. I get invited to weddings but not many other social events, like barbeques.”
- “Some people with disabilities have problems with social skills like [initiating] a conversation, making friends but also keeping the friendship going.”
- “I am bored out of my own brain. I am ready to go out but [have] no one to go night clubbing [with]. Nobody’s there to go out with nobody’s there. I don’t want to take my carers. I don’t have enough friends.”



Discussion

- Passive participation (being loyal and abiding by the law)
- Active citizenship as a responsible practice (helping people and make a positive contribution)
- Citizenship is a social experience
- The bonds of ‘civic friendship’ (Reinders, 2002, p.3)
- The socially constructed barriers limit citizenship participation (International Classification of Function [ICF] model)
- Community of citizens
 - Membership
 - Friendship
 - Relationship
 - Support



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