

Staying Clear and Strong

Challenges and solutions

Polio Australia

Liz Telford 13 October 2021

Self Advocacy: A summary

We need to know

- Our rights
- What our concern is and what outcome we want
- Who to talk to and how eg assertiveness skills
- Ourselves and what we can manage

Issues that arose in the chat

- It is sometimes difficult to feel heard by health professionals
- Feelings of being disrespected and over-ridden is a common experience
- Assertiveness was not always successful
- Being assertive in this context was often draining and stressful

Some systemic problems may be

- Hierarchical medical systems
- Inadequate training of health professionals
- Agency requirements and time constraints
- Lack of understanding by health professionals of our individual experience, wants and needs

Know how this affect us

The “knowing ourselves” part of self advocacy involves understanding how these issues make us think, feel, and act.

Creating a comfortable conversation

- Let's agree on some guidelines to ensure that everyone feels heard and respected....



Mary Westbrook Disability as a Life Course 1991, Sydney University

Identified some common characteristics through study of 176 polio survivors over 5 years:

- Lack of thinking about earlier experiences
- Particular coping strategies for these challenging experiences
- The crisis of PPS leads to falling back on these coping strategies
- These old coping strategies may have become obsolete
- After contracting polio two negative experiences occur- the first in hospital: paralysis, separation, pain and often painful treatments and being dependent on distant and sometimes abusive caregivers
- The second when home again typically involved physical barriers, exclusion, dealing with devaluing assumptions. Aggression, teasing and bullying were common
- Society's negative view of disability often taken on by the polio survivor

Westbrook comments about ageing

- Over valuation of independence and control hinders positive ageing
- Celebrating our own strengths and capturing pride is the best way to face growing older

Stephanie Machel 2021

- Talks about “medical trauma” and suggests that having polio can lead to post traumatic stress disorder
- Finding a place where polio “is spoken” can be comforting but also anxiety provoking
- Assessments, discussions of energy conservation pacing or assistive technology can trigger painful memories
- Recommends a Mental Health Professional who is aware of polio and disability issues should be a part of the Health Team.
- Awareness of own psychological issues improves functioning all round

Westbrook and Machel both raise...

- Having Polio was typically a painful and isolating experience at a very young age
- Interventions were often harsh, cruel and sometimes abusive
- Early experiences exacerbated by health professionals being invalidating and/or having little knowledge of polio
- Micro-aggressions are a common experience for people with disabilities in child and adult life
- How we cope with adult emotional issues is related to earlier experiences
- Fears about talking about these psychological issues are shared by health professionals and polio survivors, both concerned about the effect it will have
- This leads to silence about the experience
- Awareness frees up emotional energy and opens new possibilities

PPV Survey Caring & Planning for the Future of Post Polio Syndrome (Oct 21)

- Survey of PPV members supports these papers
- Respondents revealed feelings of isolation, anxiety, fear and receiving negative treatment as a child
- Current feelings of lack of understanding from family and friends
- Exclusion from activities
- Difficulty accessing funding and the services they need

Maynard and Roller Model of Coping Styles

- Passer, Minimizer and Identifier labels used to describe different attitudes and behaviours typically adopted to cope with mild, moderate or severe disability
- Concludes with how each can benefit from self awareness especially when dealing with PPS and “re-rehabilitation”
- This model is limited by over generalization but was related to by many polo survivors

Let's pause and think about it

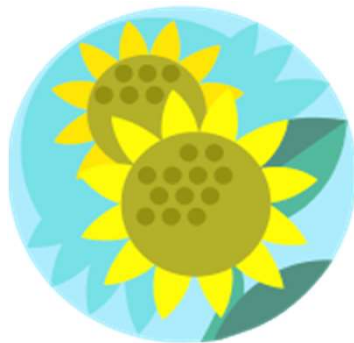
- Is this research surprising? As expected?
- Do you relate to anything?
- Not at all?
- What comes to mind?
- Does it raise ideas, thoughts, concerns?
- Back to Self advocacy...

What has all this got to do with advocating for myself?

- Recognizing what happened in the past can help us recognize what is happening today
- Remembering our experiences can help us become more effective self advocates even though it can also raise some difficult or uncomfortable feelings
- Care and compassion is a good way to manage difficult feelings

Knowing our past

- Gives us options
- Frees up energy
- Gives us understanding
- Helps self compassion
- Helps us maximize our strengths



Knowing ourselves as self-advocates

- How does my early polio experience influence my ability to advocate assertively for myself?
- What factors are involved?

Lets discuss...

Any comments, thoughts, feelings, questions...

