

FAMILY ADVOCACY WORKSHOP

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Short History of Family Advocacy in Ontario

- Prior to 1950, there was nothing but institutions – no entry to the school system, no nursery schools, no residential or in-home assistance
- In 1947 a parents' movement began in Kirkland Lake, and spread throughout Ontario and the fight for community services began
- The Association for the Help of Retarded Children was incorporated on January 31, 1952, starting with classes for 8 children taught by volunteers.
- Volunteers from the London Association started the Ontario Association for Retarded Children (OARC) (now Community Living Ontario in 1953.
- OARC eventually won Ministry of Education grants for special schools for children with developmental disabilities
- In the 1960's the focus was on pre-school service development and some services for adults.
- By 1969 the re-named London and District Association for the Mentally Retarded, opened its first group home, Scott House, on Montebello Drive.
- New nursery schools were opened and residential services expanded.
- The 1970's saw a significant push by families for their children to be included in the regular school system.
- Throughout the 1970's, 80's and 90's the push was on to close the remaining provincial institutions.
- By 1995, only three facilities, with a combined population of less than 1,000 remained open in Ontario, compared to 1974 when more than 11,000 people with disabilities lived in institutions.
- These decades were characterized by vigorous and aggressive advocacy by the provincial association in concert with adult protective service workers, other disability rights organizations, family groups across Ontario, and legal resources.
- 400 children were moved out of Homes for Special Care and a moratorium was placed on these kinds of placements by the Ministry of Health after the tragic death of Yves Soumelidis in the Ark Eden nursing home in Stroud, Ontario in 1982.
- An inquest jury found that Yves died of malnutrition, dehydration, and hypothermia. OACL had fought for an inquest that brought in 42 recommendations, and for the removal of all children from nursing homes.
- The 1980's also saw the introduction of the Special Needs and Special Services At Home Programs – the first was to ease the movement of individuals from the institutions, and the second to assist families with in-home supports.

- Community services continued to expand across Ontario as the developmental disabilities movement kept the pressure on the Ontario government.
- Vigorous advocacy and lobbying by OACL, local associations, and family organizations, assisted greatly by Anne Stafford and her team resulted in more inclusive education, competitive employment programs, nursing home reform, and legislative protections for children with disabilities.
- Consequently the 1980's saw a significant increase in funding for community-based family support programs – respite services, and inclusive employment, SIL programs, and inclusive education with Tri-Ministry assistance provided to adults living in nursing homes as **power and funding shifted from government to people.**
- The provincial association began to take an ingratiating stance with government believing the myth “you catch more flies with honey than vinegar”.
- Families got co-opted and joined the “partnership tables” government organized, thereby **shifting the agenda from families’ to the government’s agenda**
- Families, associations, and staff bought into the government’s divide and conquer agenda, thereby splitting a powerful power base.
- Service providers were intimidated by threats to their funding by government.

Decline in advocacy = Decline in Provincial Funding and Support

- With the demise of forceful advocacy by OACL and others, family organizations, and local associations, the 1990's saw a marked decline in provincial government funding for developmental services – wait lists increased, and individuals and families suffered.
- Failing to heed the warnings of its own internal policy analysts that the government was skimming funding from the deinstitutionalization initiative, OACL continued to support the government.
- The cost of this, as the analysts predicted and history has shown, was:
 - **low pay and high turnover of staff,**
 - **unionization, strikes, the inability of local associations to meet the needs of individuals with dual diagnosis and challenging needs,**
 - **the subsequent re-institutionalization of individuals in for-profit nursing homes**
 - **the government’s failure to adequately fund the Special Services at Home program.**

Why Advocacy?

- Without it, individuals with developmental disabilities and their families suffer.
- It is the only way to ensure equity, support and protection of the rights of people with disabilities
- Government gets a free pass and is able to duck its responsibility to the most vulnerable people in society
- The only ones who benefit are for-profit nursing homes, hospitals, and jails.
- Advocacy is not a “nice to have” it is a “must have”

Advocacy: A truism

“First they ignore you, then they laugh at you, then they fight you, then you win” (Gandhi).

Definitions of Advocacy:

Individual Advocacy: A means of amplifying someone’s voice, and pursuing her or his objectives according to her/his instructions, while transferring advocacy skills to her/him, thereby promoting self advocacy.

Systemic Advocacy: The means by which oppressive systems, policies, practices, and laws that negatively affect labeled groups are challenged and changed.

What Advocacy Is And What It Is Not

Advocacy Is:

- ✓ Doing your research
- ✓ Developing a comprehensive plan that anticipates counter actions
- ✓ Confronting the issues, not the people (being respectful – pushing back only if pushed)
- ✓ Sticking to your agenda and not being co-opted
- ✓ Dressing and behaving professionally

Advocacy Is Not:

- X Being unprepared without appropriate research
- X Going into an advocacy initiative without a plan that anticipates adversary’s actions
- X Venting your spleen on authority figures because of personal issues
- X Not sticking to your agenda/being co-opted
- X Looking unprofessional

Do's and Don'ts

- Remember what you are fighting for and stick to your agenda – do not get sidetracked on interpersonal issues, or others' agendas.
- Do not be overly impressed or intimidated by people in authority
- Have well defined ethics, and remain free of conflict of interest
- Develop an extensive knowledge of the system in which you are advocating
- Scan the environment, identify key decision makers, allies, and possible adversaries
- Be articulate in spoken and written communication

Developing An Advocacy Plan

- Research your issue** – have facts and figures, as well as human interest stories at your fingertips
- Determine what your resources are** – human and material, and what you can reasonably accomplish with what you have
- Identify who your allies and possible adversaries might be**
- Use root cause questioning to determine the underlying issue and address that (follow the money trail)**
- Set your goal(s), strategies to meet the goal(s), who will take part, and the target date**
- Anticipate the other side's arguments** and have counter arguments ready
- Identify and research your key decision maker**
- Involve experts**
- Use low, medium, and high profile strategies, escalating gradually**

Low Profile Strategies

- Behind closed door meetings
- Letters of complaint
- A public policy brief distributed to key decision makers

Medium Profile Strategies

- Meeting with the Opposition parties
- Framing questions for the Ontario Legislature
- Organizing a letter writing campaign
- Filing a formal complaint or FOI request
- Organizing a public meeting
- Organizing a boycott

High Profile Strategies

- Cultivate and use press contacts
- News conference or press release?
- Picketing a legislator's riding
- Leafletting a legislator's riding
- Target a legislator for defeat in an election

Researching The Issues: Information Resources

- Freedom of information <http://www.ipc.on.ca/>
- CD Rom searches
- Internet
- Libraries – medical, legal, university, community
- Registry offices/inspection branches
- Corporate searches
- Newspaper clippings

Know Your Adversary

- John Milloy was elected to the Ontario legislature in 2003 as MPP for Kitchener Centre.
- In October 2011, Milloy was appointed Minister of Community and Social Services and Government House Leader.
- Previously he served as the Minister of Training, Colleges and Universities, Minister of Research and Innovation, and Parliamentary Assistant to the Minister of Intergovernmental Affairs.
- Before becoming an MPP, Milloy was responsible for **public affairs at the Centre for International Governance Innovation in Waterloo**. He has worked for a series of provincial and federal politicians, including as Legislative Assistant to Prime Minister Jean Chrétien.
- A graduate of Carleton University and the London School of Economics, Milloy received his doctorate in modern history from the University of Oxford where he was a Commonwealth Scholar.

Researching The Issues: Human Resources

- Cultivate a range of experts
- Clip articles related to your issue and note experts quoted
- Contact authors of related books
- Ask university departments for research help

Writing An Effective Letter of Complaint

Ineffective

- X Exaggerate
- X Rambling
- X Mix facts with opinion
- X Vague – does not ask for anything specific
- X Spelling and grammar errors
- X No deadline for response
- X No request for response in writing

Effective

- ✓ Lets facts speak for themselves
- ✓ Concise and to the point
- ✓ States facts – often in chronological order
- ✓ Asks for specific action
- ✓ Free of spelling and grammar errors
- ✓ Provides a deadline for response in writing
- ✓

What An Effective Letter of Complaint Looks Like

October 28, 2012.

FOR YOUR EYES ONLY

Hon. John Milloy,
Minister of Community & Social Services,
6th Floor, Hepburn Block,
80 Grosvenor Street,
Toronto, Ontario. M7A 1E9

Dear Minister,

I am writing on behalf of the Ontario Community Services Coalition which represents transfer payment agencies, family organizations and staff providing assistance to individuals with developmental disabilities. We are deeply concerned about the impact of your Ministry's "transformation agenda" for developmental services. At the present time, there are serious issues in this system as a result of this agenda. Specifically, there are long waiting lists for Residential accommodation, the Special Services at Home and Passport Programs are grossly underfunded, leaving hundreds of individuals and families without support; service providers are unable to meet the needs of individuals with challenging behaviors and/or high requirements for support; professionals working in this system are grossly underpaid and turnover is high,

causing needless disruption in the lives of individuals being served, and strikes have become commonplace.

This situation is utterly unacceptable to this Coalition. We are, therefore, seeking a meeting with you immediately to discuss the current crisis in this system.

A response by no later than November 16, 2012 would be appreciated.

Yours truly,

What If He Doesn't Respond?

- Press release "Coalition Requests Meeting With Minister on Developmental Services"
- Picketing his office
- Leafletting his riding
- Start a Facebook Campaign
- Question in the Ontario legislature

Making Your Case

- You decide how many are coming and who – not the Minister's Office
- Bring your sons and daughters
- Make points one at a time, ad libbing – refer to notes, but do not read
- Make eye contact with those in the room, longer eye contact with key decision maker
- Substantiate your points with sources or examples.
- Dramatize by using graphic information, but do not exaggerate
- Use pictures or video if appropriate
- Speak in a slow, purposeful way (watch your breathing) – project your voice
- Involve your audience – ask questions, make statements referring to them by name
- Dress in navy, black, khaki, or gray with white
- Provide copies of your presentation or a letter detailing what you are requesting
- Wind up your presentation with a direct and specific appeal
- If you are nervous, don't mention it

Tips When Meeting With Key Decision Makers

- Take control – enter room purposefully
- Firm handshake and eye contact
- Begin immediately by thanking the person and jump right into the issue
“Thank you for meeting with us today. As you know we are here to discuss
- Sit across from the most powerful person in the room
- Ask the person questions that demand answers “Do you agree that developmental disability services are underresourced across this province?” “What do you see as the priorities?”
- Say what you want and produce the documents – facts, figures, anecdotal information, expert sources – to prove it
- Anticipate the “no money” argument and point out that priorities are the issue – point to where money has been misspent i.e. nursing homes rather than community support for people with developmental disabilities; money skimmed from deinstitutionalization that has left the system struggling; funding for bureaucracy rather than service

What’s your Plan?

- What is your priority goal?
- Who are the key decision makers?
- What resources might you have to commit to an advocacy campaign?
- What strategies could you pull off?
- Who are your allies/possible adversaries?
- What experts may be of help?