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# Empowering Families

## THE “STEP APPROACH MODEL” FOR EFFECTIVE ADVOCACY

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**In 1991, Dale Munro published an article in *Canada’s Mental Health* entitled “Training Families in the ‘Step Approach Model’ for Effective Advocacy.” It received widespread attention and was republished in the newsletters of several Canadian organizations including Autism Society of Ontario [now Autism Ontario]. In the article which follows, Dale has updated and revised his original paper.**

*“Canadians complain just as much as Americans, but not as well... Individually, we tend to be pushovers!” Phil Edmonston (2013)*

**FAMILIES OF CHILDREN**, teens and adults with ASD (and related diagnoses) sometimes lack the necessary skills and confidence to raise concerns comfortably and constructively with human service systems. Yet, families sometimes have more real political “clout” in affecting change in educational, developmental, social service and health systems than they realize at first (Schields, 1987). When families raise concerns, they stand outside of existing systems. They have access to sources of influence (e.g., mainstream and social media, top government or bureaucratic decision-makers, self-help and advocacy groups) not ordinarily available to people employed by service organizations. This article argues that families of individuals with ASD can benefit greatly from learning the “Step Approach Model” for effective advocacy.

“Effective advocacy” can be defined as a non-violent empowerment and support process, through which families of people with ASD can constructively express dissatisfaction and contribute to creative solutions to problems existing in human service systems. The intent of effective advocacy is twofold: first, to resolve concerns and meet the needs of families and their relatives with ASD; and second, to open up communication channels so that raising concerns is perceived as beneficial by others in the helping process – e.g., individuals with ASD, other families, professionals, education and agency managers, bureaucrats and politicians.

### Ten Rules for Improving Advocacy Effectiveness

Why do some families get what they want when they advocate, while others do not? Through the years, successful family advocates have taught us the importance of adhering to the following common sense rules.

#### Rule #1: Never use a cannon where a pea-shooter will do

When family members are overly negative, aggressive or obnoxious, they risk being avoided and labelled “sick,” and often alienate other families, potential supporters and problem solvers. When advocating, it is usually wise for family members to speak in a calm, polite, dispassionate, but sincere and firm manner (Baskin & Fawcett, 2007; Edmonston, 1984). Probably 90 percent of family concerns can be resolved quite simply at or near the front-line (school or agency) level. Coming on too strong, too early with top managers or powerful outsiders (e.g., elected officials, lawyers, mainstream or social media) usually only complicates attempts to address problems. Families need to understand that advocacy is more about building relationships with key members of “the system,” rather than shouting, embarrassing decision makers and breaking

down proverbial doors.

#### Rule #2: Help professionals, so they can help you

Families should keep a well-organized file where all pertinent information regarding their relative with ASD is kept. This is where professional assessments, school and agency reports, meeting minutes, correspondence, service commitments, a log of important phone calls and e-mails, and other information can be kept. Maintaining a proper “paper trail” not only assists families, but can be really helpful to new professionals or services, when they become involved. One creative parent, after watching the movie *Jerry McGuire*, began to use a “Help me help you” philosophy when dealing with

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new professionals and services. She made multiple photocopies, or electronically scanned each professional report or pertinent document, so that every new professional or service that became involved was given a complete portfolio of information regarding her son at the very first meeting (J. Wright, personal communication). This saved the professionals and service representatives weeks of time, because they did not have to request, then wait for past information to arrive. It allowed the actual consultation, planning or intervention to begin sooner.

#### Rule #3: Get the big picture

In order for the system to respond to particular needs, it is helpful for family members first to visualize the wider context in which problems exist and what factors may be influencing the decision-making process. Families should be aware that decisions can be affected by

factors such as professionals and managers being overworked or “burned-out;” that local politics and in-fighting can delay responses; and that there are always other families, individuals and disadvantaged groups in other fields simultaneously demanding service resources. By developing a more accurate understanding of “the big picture,” family members can begin to determine their goals realistically and start the all-important task of answering key questions, such as: “What specific outcome do we really want to achieve?” and “Who are the pivotal people in the system, at this point in time, who can help solve our problems?” As Craig Schields (1987) so aptly stated: “The system helps those [families] who know the system!” He further explained:

“Because the system continually changes and the needs of your child will change, getting to know the system can become a continuous task for parents. Fortunately, it’s a bit like working a jig-saw puzzle; it gets easier as you go along and as more of the pieces fall in place.” (p. 56)

#### Rule #4: Time your advocacy strategies carefully

Family members sometimes fail to recognize that proper timing is essential in order to have concerns heard and addressed promptly. To ensure proper timing, a family should ideally do three things: first, raise concerns only when their own motivation and energy level is at its highest; second, complain and advocate when the potential problem solver is most willing and able to listen and deal with the concern (e.g., when public opinion is on the family’s side, or when new resources have just been announced); third, identify needs early to avoid crises later (e.g., begin post-secondary transition planning when the student is 14 rather than age 18 or 21).

#### Rule #5: Use the cards you’ve been dealt

Too often, families fail to “use the cards

they've been dealt" to turn their particular situation to their advantage. For instance, most families of people with ASD possess inherent cohesion, skills and resources that can greatly facilitate the advocacy process. Some family members are excellent public speakers or motivators. Others have group facilitation or organizational skills; bookkeeping, legal, mediation, research, entrepreneurial or clinical backgrounds; "friends in high places;" or they possess personality strengths such as determination and persistence (i.e., "I never accept 'No' for an answer!"), charisma and real commitment to improving the lives of others. In really desperate situations, family members can also call upon the public's and media's sense of natural compassion for people facing serious challenges. And families should never forget that people with ASD can sometimes take the lead, or work side-by-side with their families, in the advocacy process.

#### **Rule #6: Don't go it alone**

In terms of effective family advocacy, "going it alone" is usually unproductive, exhausting or even destructive. There is strength, power and support in numbers. For instance, if a parent is going to a meeting at the school, agency or professional's office, it is wise to take part of your "support team" (a witness) with you to take notes or as an extra set of ears – e.g., one's partner, friend or a trusted professional (Baskin & Fawcett, 2006; Edmonston, 2013). Whenever possible, families should work closely with established groups, such as Autism Ontario, professional organizations and agencies – and influential community members – in trying to secure what they need. Equally important, parents, siblings and people with ASD in one family need to coordinate their power and inherent skills with those in other families. Tremendous support can accrue from finding even one other family that shares and understands your concerns (e.g., in person or on Facebook). If more families join in, an

even more potent instrument for affective change can develop. Shared discontent, combined with opportunities for a little fun and fellowship, is the fuel that maintains cohesion in such grassroots advocacy and support groups (Alinsky, 1971; Edmonston, 1984).

#### **Rule #7: Be willing to compromise!**

Politics is the art of compromise, and families today must advocate in a very political world. Unfortunately, the word *compromise* often carries with it implications of weakness, vacillation, betrayal of ideals or surrender of moral principles. Yet, Saul Alinsky in his classic book *Rules for Radicals* states that compromise

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is often a key and beautiful word in resolving concerns or addressing needs. In the end, results – not revenge or egotistical self-interest – should be the family's overriding goal. Finding common ground and negotiating a workable compromise can be a means of creating meaningful results for everyone concerned. In particularly intense disputes, families or organizations may find it useful to involve an impartial mediator who can help open up communication and encourage brainstorming of creative solutions for resolving complex family-system disputes (Munro, 1997).

#### **Rule #8: Humanize the concern**

In order for family members to be successful advocates, they should try to humanize the presentation of their concerns in such a way that decision makers feel the uniqueness, the validity and the urgency of the request. An elected representative may find moving personal testimony from a parent (or a group of

parents) far more powerful than mountains of statistics. It is sometimes helpful for family members requesting something to take their relative with ASD with them when approaching decision makers – to drive home the reality of the family concerns. Other times, attaching a video or using social media to illustrate the challenges associated to one's relative can have a powerful impact.

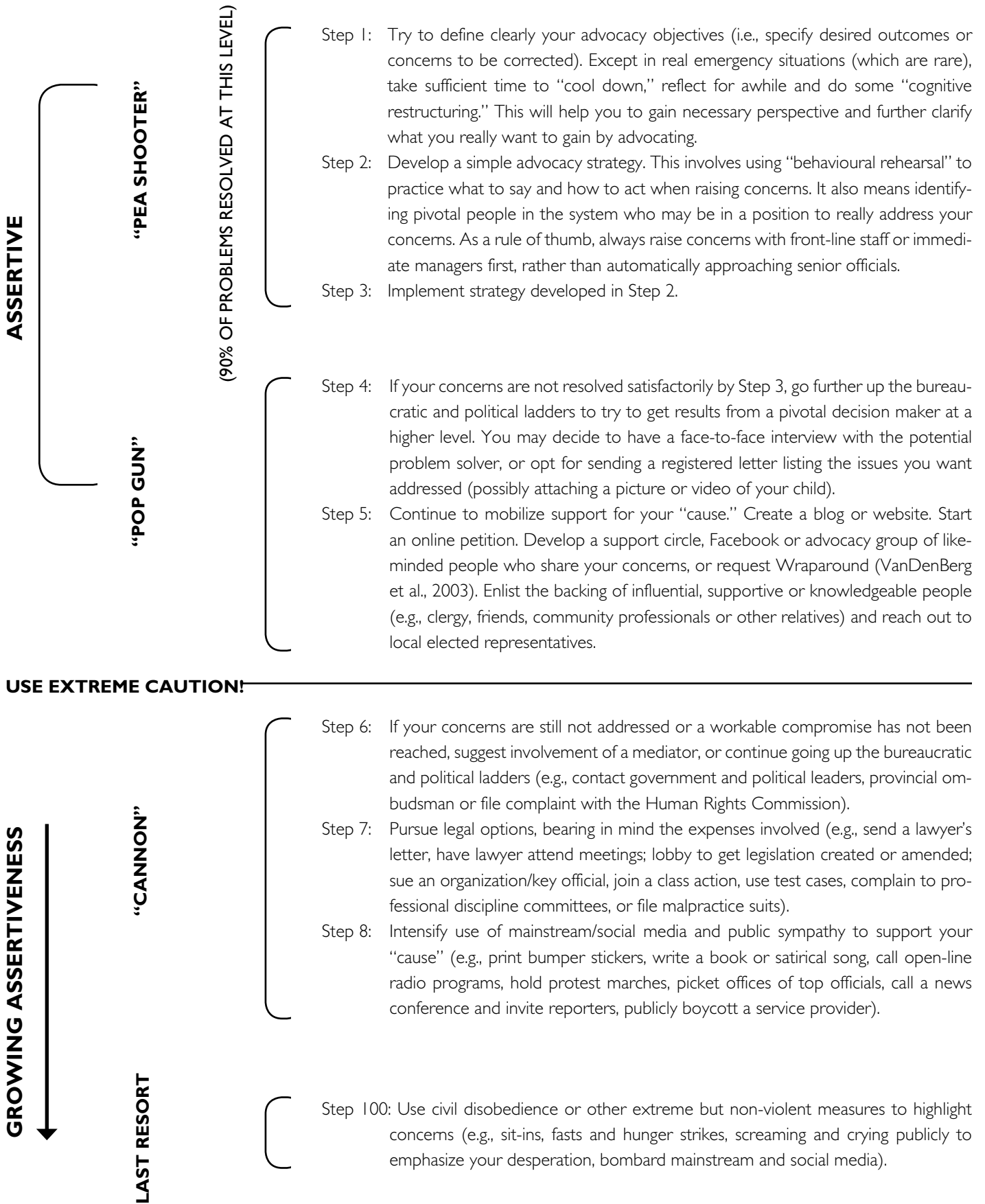
#### **Rule #9: Practise good stress management**

Sometimes advocacy can be empowering, even exhilarating for families, as system hurdles are overcome. Other times, advocacy's adversarial nature may be viewed by families as stressful, time-consuming and demoralizing as they come up against "brick walls" (Nachshen & Jamieson, 2000). With this in mind, family members must carefully pace their advocacy efforts, to avoid physical or emotional exhaustion ["Remember, this is a marathon, not a sprint!"]. They may even have to back off from advocacy for awhile when the frustration becomes too intense, their personal or work life is suffering, or other personal needs become a priority (Baskin & Fawcett, 2007). Family members need to ensure they are practising good stress management – e.g., regular physical exercise, proper nutrition and sleep; countering negative self-talk by rehearsing positive self-statements; setting aside time for meditation or other mindfulness-based practice such as yoga; going for counselling if needed; and sustaining healthy relationships with one's partner, a co-parent, the individual with ASD and his or her siblings, and other supportive people.

#### **Rule #10: Express appreciation and show support to helpful problem solvers**

Sometimes family members who have had their concerns successfully addressed fail to thank or otherwise support helpful professionals, managers and decision makers. This ultimately can be

**Figure 1: The “Step Approach Model” for Effective Family Advocacy\***



**\*“Never use a cannon where a pea-shooter will do!”**

self-defeating. Professionals, managers and others from whom families request help are human too, and do not like being taken for granted. In the politically charged world in which decision makers and professionals work, a little sincere appreciation (that might even make the problem solver look and feel good) goes a long way towards ensuring future cooperation.

### Learning to Advocate Assertively

Effective advocates are almost always assertive advocates. Unfortunately, many family members confuse assertiveness with aggression (see Rule #1), or fluctuate self-destructively among submissive, passive-aggressive and aggressive styles of complaining. To clear up some of these misunderstandings, *assertiveness can be defined as the direct, honest, comfortable and appropriate expression of feelings, opinions and beliefs, through which one stands up for his/her own rights – without violating the rights of others.*

In order to enhance their assertive skills, family advocates often can benefit from systematic training in two useful techniques – “cognitive restructuring” and “behavioural rehearsal.” *Cognitive restructuring* allows family members to get their anger, frustration and other potentially destructive emotions under control and creatively channelled into socially appropriate outlets. Family members are taught how to identify their negative thoughts or beliefs (cognitions) and

re-think (restructure) them in a more rational, positive and constructive manner. This technique allows family members to “cool down” and gain necessary perspective before deciding on the most effective course of action.

*Behavioural rehearsal* is another useful technique. This involves the systematic use of role-playing to help family members experiment with, rehearse and consider various advocacy strategies before actually confronting real people and situations. Although family members can use cognitive restructuring and behavioural rehearsal without drawing on outside assistance, it is often helpful to enlist the counsel of others (e.g., “level-headed” friends, support group members or professional counsellors) when using these techniques. By using these two approaches, family advocates can usually change their perception of “the enemy” (e.g., professionals, managers, bureaucrats or politicians). They can begin to reframe these people more positively as “potential problem solvers,” and to perceive difficult situations more optimistically.

### Extreme Caution! Going Well Beyond Assertiveness

There may be a point in the advocacy process where very confrontational approaches (e.g., public crying and screaming, social and mainstream media bombardment, civil disobedience in the form of sit-ins) may be perceived by

families as the only avenue left to them. Some families have successfully used such methods *in rare circumstances* when all assertive options have been exhausted, or in “life and death” crises. But families must be cautioned that it is worth exploring all other options *within the system* before going outside it. In fact, the decision to “go over someone’s head,” or to apply any type of outside pressure (political, legal or public) to the system is a serious one. Families should not rush into something they may regret later. And it must be unequivocally stated that under no circumstances can violent or highly illegal approaches be justified – e.g., physically assaulting others or destruction of property. (Alinsky, 1971; Edmonston, 1984; Schields, 1987)

### In Summary: The “Step Approach Model”

Figure 1 (see page 30) illustrates the overall approach for effective family advocacy – the “Step Approach Model.”

Using this advocacy model, families are encouraged to use a graduated “baby step” approach when raising concerns, starting with the least intrusive strategies and, if needed, slowly moving from assertive to possibly more aggressive approaches. If initial efforts do not work, families can consider (with caution) continuing up the bureaucratic, legal and political ladders. In the end, family members often are empowered by the knowledge that they have had the courage and commitment to “go to bat” for their relatives with ASD – that they have stood up for them and, indirectly, for others like them! ■

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