BRINGING UP THE ROOF

An evaluation of the Advocates Against Abuse Project













The members of the *Advocates Against Abuse* Steering Committee acknowledge the tremendous work and authorship by Melodie Cook and Adriana McVicker in the "Bringing Up The Roof" evaluation report and thank Dr. Kathryn Church for her contributions as the Research Advisor.

The members of the *Advocates Against Abuse* Steering Committee are:

Adriana McVicker Brad Verfaillie Dave Hingsburger **Debbie Phillips** Gerard Phillips Joe Jobes Kevin McMullan Lee-Anne Dupuis Lisette Lanthier Lynne Shepley Melodie Cook Nancy Wallace-Gero Pam Pearce **Ron Coristine** Steve Snider Sue Rocheleau Ted Armeland Jeremy Hart (deceased) "Advocates Against Abuse is an incredibly powerful and innovative model of training that has the potential to continue to transform our agency to be even more responsive and respectful towards people supported – while keeping them safer!"

-Nancy Wallace-Gero, Community Living Essex County

"Advocates Against Abuse – the concept is wonderful, the implementation unique and the results, phenomenal!"

-Lu-Ann Cowell, Community Living Chatham-Kent

"The Advocates Against Abuse project demonstrates two things; first, people with disabilities will rise to the occasion when given the opportunity to lead, second, we need to have the courage to make those opportunities happen."

-Dave Hingsburger, Vita Community Living Services



INTRODUCTION

Although there is not a great deal of research in Ontario on the amount of abuse towards people who have an intellectual disability¹ there can be no doubt that when it comes to abuse, the statistics that are available are scary. While the rate of violent treatment for people who have a disability in Canada is rated at twice as much as that of people who do not have a disability², the rates of violent crime for people who have an intellectual disability are even higher³. Successful ways to help keep people safe involve education of the people themselves to be armed to recognize and stop abuse⁴.

Under the new Social Inclusion Act regulated by the Ontario Ministry of Community and Social Services, in certain cases it is mandatory that suspected abuse of a person supported must immediately be reported to the police. It is also required that abuse prevention training be provided to people who receive support and to any employees of a service provider agency. While these policies make service provider agencies more accountable, agencies must also put these policies into practice in the most effective way to keep the people who receive support safe.

Research has described that the voices of people who have a disability are usually missing whenever there is talk of inclusiveness in education, curriculum development and methods of teaching⁵. This sends a message that people who have a disability have less knowledge and causes them to have less power and less influence on a system that affects them.

⁴Hingsburger, 1995; CLO, 2010; Powers and Oschwald, 2004; Brownridge, 2006; Eastgate et al., 2012; Miltenberger et al., 1999

¹Community Living Ontario, 2010

² Perrault, 2009

³Mansell in CLO, 2010; Sobsey et al. 1995

⁵ Vlachou-Balafouti in Barton, 2001

What is Advocates Against Abuse?

Advocates Against Abuse (AAA) is abuse prevention training that is taught by people with disabilities to people with disabilities. The project was created in response to the need to address the extremely high incidents of abuse that occur involving people who have an intellectual disability. In July of 2011, Community Living Essex County received funding through Green Shield Canada's Community Giving Program to develop a peer training model for the prevention of abuse of people who have intellectual disabilities. At that time, the idea had not been attempted in Canada but a similar approach had been successful in California. Additional partners for the project were Community Living Windsor, Community Living Chatham-Kent, Christian Horizons, and Vita Community Living Services.

"Since I've joined AAA it's made me become a much better advocate and human. I feel that it has really changed me for the better. Being a Trainer has really given me more confidence and strength and I feel like a role model for other individuals supported through our organization."

-Jennifer LeBlanc, Community Living Windsor

"Dave Hingsburger made the point that to maintain the interest of people with disabilities, it is important that the training be delivered QUICKLY - not slowly. I didn't buy it. It seemed counterintuitive to me. However, seeing is believing. When I saw the course being delivered and all present completely engaged and participating, he was right. Slow can be boring, and the Advocates Against Abuse course is anything but boring."

-Steve Snider, Christian Horizons

Who is a Part of AAA?

Four groups made up of 22 Trainers and Helpers from:

- Community Living Essex County
- Community Living Windsor
- Community Living Chatham-Kent
- Christian Horizons

The Trainers are Self-Advocates. The Helpers are Direct Support Employees.

One Steering Committee made up of Self-Advocates, Support Staff, Managers and Directors.

What did we want to do?

The AAA project had originally set out to accomplish specific goals;

- Provide education to people who have an intellectual disability on how to identify and report abuse
- To create a curriculum in accessible language that is straight forward, interactive and taught by Trainers who are self-advocates
- To challenge the traditional way of teaching people who have a disability
- Meet the requirements of M.C.S.S. Ontario Reg. 299/10 on abuse prevention training
- Increase collaboration and connections between people supported and service provider agencies and provide the same training on abuse prevention

How did we evaluate Advocates Against Abuse?

Bringing up the Roof

Bringing Up the $Roof^{6}$ is the final report of the process, evaluation and outcome of the Advocates Against Abuse training on abuse prevention.

The Evaluation

Overall, the evaluation needed to answer two questions:

- **1.** Did people who were taught by Trainers who had an intellectual disability using an accessible language curriculum learn the material?
- 2. What other things did the people involved in the project as Participants, Trainers and Helpers get from the experience?

⁶ The phrase "Bringing Up the Roof", stated by a Focus Group member, described the core of what AAA truly represented; not just raising the roof to celebrate a job well done, but bringing up the roof on the house of self-advocacy and raising the bar on expectations of service providers.



In order to evaluate the first question, the Steering Committee decided to hold four AAA training classes with the same Trainers and Helper. At the end of each AAA class, a review would be done by asking the audience members six "wrap up" questions that targeted the main areas that were being taught in the class. The "wrap up" questions were created by referring to a post-test originally developed by Dave Hingsburger as well as suggestions from a few committee members who were experienced in abuse prevention training. The questions were asked randomly and involved as many audience As the "wrap up" members as possible. questions were being asked, one of the researchers sat at the back of the room and quietly wrote down the answers. The answers were then used to evaluate which parts of the curriculum seemed easy to understand, and which parts people seemed to struggle to understand. The answers from the "wrap up" questions were used to make note of the parts

of the AAA curriculum that needed to be strengthened. The researchers felt that by asking "wrap up" questions, they could note whether learning had taken place and could do so in a way that did not stand out to the audience and would not cause any anxiety concerning past experiences with testing.

To evaluate the second question concerning the experiences of the people involved in the project, it was decided that four Focus Groups would be held within the same week of the training. The first two Focus Groups involved the class participants from the four AAA training classes. In addition, one Focus Group was held for the Helpers and one was held for the Trainers. It was through the Focus Group discussions that the researchers were able to really hear and understand what people thought of the AAA training as well as what people personally experienced during their time as an audience member, Trainer or Helper.

8 Key Findings

Some of the most valuable lessons from the AAA project were seen by the researchers as the project struggled and unfolded. It was often the unexpected struggles of the project that held more value than the original goals.

1

IT WORKS!

The discussions from the Focus Groups and the answers from the "wrap up" tests confirmed that learning had happened. What was expected to be learned from the AAA curriculum was easily understood and was easy to remember. To understand how this learning changes over time it would be helpful to have audience members of the training sessions invited back to participate in a second Focus Group months after their first training to see what parts they remember.



A GOOD TEACHER IS...

Good teaching was not defined by having a label of "disability" or "no disability" but rather teaching was enriched by teachers having the lived experience of what was being taught. Class participants identified that having a disability was relevant and helpful. Trainers were described as being prepared, encouraging, fun and involved in what they were teaching. Trainers were able to be flexible in their style of teaching and were able to "teach from the heart". Class participants shared that they really liked the "slap-stick" kind of humour that the Trainers used as they explained parts of the This helped the audience curriculum. remember certain role plays and had a direct effect on learning the course material. Discussion from the Focus Groups also revealed that the training seemed better and had greater

impact when it was taught by Trainers who were unfamiliar.

3

WHOSE ROLE IS THIS ANYWAYS?

Having people with disabilities as AAA Trainers and their support staff as Helpers encouraged a shift of power; the person with a disability was in control of the teaching, not their support staff. In the beginning, some Trainers struggled with trying to figure out exactly what being a Trainer was all about. After practicing and learning, Trainers soon came to realize that they were the teachers and they were the experts. As Trainers became more familiar with ways to prevent abuse, they began to use this information in their own lives outside of being a Trainer. All of the Trainers identified themselves as role models for the work that they had done teaching others about abuse prevention and their audience found that the self-advocate peer Trainer was someone that was easy to relate to.

The role of a Helper was to only help and never lead the Trainers in any of their training. Many Helpers felt confused as the training groups were finding their roles. Helpers described their role as "walking a fine line" and the challenge was to determine the times that they were needed to step in and help, from the times that they were needed to stay quiet and step back. In the beginning, both the Trainers and Helpers felt confused and struggled with their roles. However, both groups felt that going through that time of confusion helped them develop a solid understanding of what being a Trainer and Helper was all about.





THE SIMILAR RELATIONSHIP

Helpers came to realize that the relationship between the Trainer and the Helper was very similar to that of a person receiving support and a support worker. Helpers originally saw these two roles (AAA Helper and Direct Support Staff) as being different. Helpers saw the similarity of how they should perform both roles in its simplest form: be supportive without creating a personally dependent relationship with the person receiving support. Overall, Helpers came to realize that their role was to guide the Trainers to independently discover their roles by giving them space to learn through the ups and downs of the experience.

developed from the discussions of the Steering Committee. The steps of the process then trickled down (and eventually back and forth) to the potential Trainers and Helpers which guided the successful outcome of the AAA project. According to the Trainers and the Helpers, one of the most significant steps of the process involved choosing the right Trainers and Helpers for the project. The selection process included an interview process⁷ and a two-day training workshop. Trainers also participated in weekly practices and bi-weekly joint practices with Trainers from partner agencies. According to the Trainers and Helpers these steps influenced the level of commitment to the AAA project and raised the bar of expectations of professionalism and follow through from the candidates.



THERE NEEDS TO BE A PROCESS

To make sure that a new project or system is successful, there needs to be a plan of action. The process for the AAA project

[']An interesting finding from discussing the interview process with the Trainers was that the majority of them were prepared to not be chosen before they had even gone for an interview. *"Try again next year"* seemed to act as protective words against feelings of failure and disappointment.

6

LOOK WHO'S TALKING NOW!

Programs and services that are used by people who have an intellectual disability are rarely evaluated by the very people that use them. Throughout the evaluation of the AAA project, many audience members, Trainers and Helpers voiced their thankfulness for the opportunity to give feedback. The groups involved stated that the opportunity was not only appreciated, but that it was completely new. The participants of each of the Focus Groups had a lot to say about their experience, about what worked well and about what and how other elements could be altered for additional success. It is the feedback from all of those involved in the project that has helped AAA become what it is today.



"SUPPORTIVE" LIVING AS A BARRIER

People in the participant Focus Groups thought that because "group living" situations supported by service provider agencies have rules and policies, they are the safest place to live. This is not in keeping with abuse statistics and could give the people that live in this type of environment a sense of security that is not true. This could also excuse the need for those who live in these types of situations to develop and practice their own skills of self-protection. According to the participant Focus Groups, "people with disabilities might not know that they can say 'no' to a support staff", or that they could disagree with how things are done.



Sometimes direct support employees can offer too much support and can even take control of everyday situations when the person supported should be in control. Through Focus Group discussions many of the Helpers were able to look back and see situations where they thought they were being helpful, but were actually being confusing and unsupportive. As a service sector, we need to better educate direct support staff about what their role is supposed to look like. This will help them so that they can be prepared to work beside the people they support and to never lead them into a personally dependent relationship.



IT TAKES THE COMMITMENT OF EVERYONE

The success of the AAA project depended on the commitment of everyone involved: Trainers, Helpers, and Steering Committee members. This dedication ensured the AAA project was successful in following through with what it set out to do including meeting the expectations outlined in the MCSS Ontario Regulation 299/10. The involvement of the Steering Committee members made sure that the Trainers and Helpers had a place to practice their skills, the AAA message was consistent and smooth, problems were identified and resolved quickly and the Trainers and Helpers were involved and motivated during the process.

Without the investment of time and energy, a great idea becomes nothing more than an idea. Essentially, the members of the AAA project took the time and energy to mold a great idea into meaningful training that keeps people safe and creates positive outcomes for change.

"The thing I was most impressed with about the whole journey was to see people develop skills to become amazing trainers. They are good because they are talented, dynamic and dedicated. The fact that they had been labeled as disabled was simply a footnote to an incredible accomplishment."

-Kevin McMullan, Community Living Essex County

"Watching people with an intellectual disability teach others is a true testament to their abilities! Watching the trainers "come alive" as they teach others about abuse prevention is inspiring and exciting!"

-Sheri Franklin, Community Living Chatham-Kent

New Directions

Looking back on both the process of the project and the discussions from the Focus Groups, some ideas for future research include:

1. The "Parent" and "Child "reference when discussing the role of the direct support employee and a person with a disability.

People with disabilities often described other people with disabilities as "kids". Similarly, the Helpers shared that they "felt like a proud parent in the crowd" as they watched the Trainers train. These references should be looked into as it may shed some light on certain views that are still held within the developmental service sector, and it could also help define the idea of being caring and supportive balanced with being professional and respectful as a direct support staff.

2. The feeling of "losing control" that was felt by direct support employees as they were figuring out their role as a Helper.

Further studies should look into the details of the relationship between support staff and person supported. Future research should also look at the factors that lead people to choose to work in the sector as well as the messages they seem to get concerning what their job is all about. Perhaps there are key principles that would help create a better understanding of the role of support staff and help create best practice guidelines for employees.



3. Exploring different strategies that help encourage learning in a classroom environment for adults who have a disability.

The AAA project has documented the pioneering of some very successful strategies to enable a friendly learning environment for adults with disabilities. Further research should look at why these strategies work best. This could influence change in the traditional views of teaching and learning with adults with disabilities and could influence the way in which service provider agencies conduct other training beyond abuse prevention.

4. The problem that is caused when the message is not in line with how it is delivered.

Trying to help people arm themselves against abuse in a way that makes the service providers look like "the experts" can create a misleading message for people with disabilities that the dangers of abuse lay outside the service system. In addition, suggesting that services exist to assist people with disabilities in having their voices heard while at times denying people's right to shape those services limits our true success.

Further research in these areas would help the Developmental Service Sector better identify ways to make sure that both services and messages are delivered in a way that honours the safety, well-being and perspective of people receiving support.

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