

Service, Support and Success

The Direct Support Workers Newsletter**Keeping the ME in Media:
Thoughts, Ideas and Tips for Supporting People
with Intellectual Disabilities to Use Social Media**

By: Donna Lee

Facebook, Twitter, Blogger, YouTube, Tumblr, Pinterest.

These and other social media have become common pastimes for many of us over the past few years. We may use them for keeping up with friends, linking with people who have common perspectives, sharing our opinions and experiences, staying informed about issues that matter to us, or playing games. Think for a moment about your own use of social media – what do you use it for? What do you get out of it? What benefits does it have for you?

Social media are also enjoyed by many of the people we serve, although those in supporting roles often express concern about vulnerability, safety, privacy and costs. While these can be valid concerns, it's important not to let moral panic about social media restrict people's access to an important source of fun and connection. Instead, let's aim to provide information and support that helps people become safe and savvy social media users and develop an understanding of the unique boundaries and opportunities that come with use of the internet. Boundaries that determine what belong to 'me' and what's okay to share on any form of social media. Opportunities for presenting the 'me' that I determine best represents who I am.

First, let's think about what the benefits of social media are for individuals with developmental disabilities. Of course the same benefits of connecting with friends and family that others enjoy applies to the people we support as well. But additional benefits may also occur for this group. There are many disability communities, groups and self-advocate organizations that have a strong presence on social media – following or friending these groups can build important connections and facilitate involvement in important projects, events and the larger disability movement. Social media also offers users multiple ways to participate that don't all rely on being able to read and write eloquently. The use of shorthand and phonetic spelling, photos, and videos offer easier access for people with developmental disabilities, allowing them to be both consumers and creators of these media.

Historically, and still today, the vast majority of representations of people with developmental disabilities in the media are created and distributed by non-disabled people. This leads to images that often reinforce ideas of developmental disability as tragic, something to be fixed, or of people as child-like and unidimensional. Social media offers users the opportunity to be the creators of their own content and to represent themselves as they choose. This self-representation opens up possibilities for alternative portrayals of what it is to be a person with a developmental disability – possibilities that are as numerous as the number of people representing themselves and their own experiences of disabled life.

Of course one of the most important benefits of using social media is having fun! People laugh at funny photos and videos, build and manage virtual farms, exchange comments about the latest episode of Big Bang Theory, post pictures of their latest culinary creations and make plans to get together in the offline world.

What About Online Bullying and Exploitation?

It's true; there are some folks out there who will make mean or harassing comments directed at those with any perceived difference or vulnerability. There are those who will take advantage of someone who is thought to be gullible. It would be irresponsible not to warn the people we support about the presence of such bullies. However, the solution doesn't lie in restricting people's access to social media for fear that they may have a bad experience; rather we need to teach people ways to minimize and manage the risks while still enjoying the benefits of social media. Suggestions for what and how to teach are described below.

What If They Become the Bully?

People with disabilities can sometimes be the ones doing the bullying and the online environment may provide a forum for this to occur. A private disagreement with a friend or coworker can quickly escalate when accusations and name calling are posted on Facebook, especially if other Facebook Friends join in with their own putdowns of the targeted person. Again, teaching about online rules, laws and etiquette is essential to ensure that people know what behaviour is acceptable within social media and what the potential consequences of breaching those rules may be - just as we teach about such things in the offline environment.

So what exactly do we need to teach? That will depend on the individual and the type of social media they are interested in using. But here are some of the topics that need to be covered:

Signing Up and Signing In:

The process of getting started can be easy for some and an intimidating maze of captchas, passwords, and unique usernames for others. If you are an experienced social media user yourself, then you will likely be able to guide someone you support through the process – if this isn't an area you feel skilled in, then you may want to enlist the help of a coworker who has these skills. Most social media require you to have an email address and so setting up an email address may be the first thing you need to support the person to do. Once that's done, there are captchas to decipher (you know, those hard to read twisted and blurred series of letters and numbers that are designed to make sure you are human and not an automated software program), passwords to create of 4 to 16 characters that are easy to remember but difficult to guess, and usernames to come up with that haven't been used by anyone else. This is a great time to teach about the importance of keeping passwords private by not sharing them with friends or other online users. Another tip to pass on is the need to keep a record of passwords in a safe and private place.

If It's Private – Don't Post It:

Privacy is a tricky concept and it can get trickier still in the world of social media. There are the more obvious privacy rules (though not so obvious that they don't need to be taught) about not posting pictures of private body parts or activities, and not giving out personal information like your address or

banking information online. But there is also a need to explain about what topics are appropriate for general posting, what topics need to be discussed via private messaging, and what topics should stay offline. Tweeting about a great meal at a local restaurant is fine, while any conversation about the resulting indigestion later that night is something that should take place offline. Putting other people's pictures and information on Facebook or Pinterest is another area that requires teaching. Posting a picture of yourself and a couple of friends at a dance with their names and a funny description can be fun for everyone, but to be sure it's a good idea ask the people in the photo for permission to post it first. It becomes especially important to ask before posting something that might cause another person embarrassment – or better yet, don't post that photo at all. Sharing private information about others is also a no-no. Aunt Kathy is not going to be pleased if you break the news of her pregnancy to the Twitterverse.

You might create a reminder card or list to help the person remember which topics/pictures can be posted, tweeted and pinned, and which should not. Such a card might include columns for public posts, private posts and those that fall somewhere in-between and which posts and messages should go to which people. It might look something like this with the boxes filled in with topics specific to the individual:

PRIVATE – send to one person only or no one at all	BE CAREFUL – send just to those who need to know	PUBLIC – okay for anyone to see, post anywhere

Ms. Manners for Social Media

Etiquette in the world of social media is much the same as it is in the world of social interaction in general. And just like social skills for the offline world, online social skills often need to be explicitly taught. Here are a few social media social norms that warrant teaching:

- Be nice. This may seem self-evident, but sometimes people forget that there are real people with real feelings reading our posts and that being nice goes a long way in maintaining friends, followers and memberships in online groups.
- Be careful of your tone. Let people know that typing in all caps is akin to YELLING; show them how to use emoticons to clarify the tone of a message.
- Don't overshare. You know that acronym TMI? The one that stands for "too much information?" Teach the people you support how much is too much. A few posts or tweets are fine – more than 3 or 4 a day may cause your Facebook Friends to hide your posts and your Twitter followers to unsubscribe. TMI can also apply to the amount of detail that is shared in a post – no one wants to hear about the intimate details of your latest dentist appointment or a list of your aches and ailments.

- Use the delete button when someone pushes your buttons. Ignoring or deleting mean-spirited or inflammatory comments and commenters is a better way of dealing with those trying to get a reaction than engaging in an online battle with someone.
- Turn it off sometimes. No one likes it when the person they are talking to is busy texting or checking their Facebook account in the middle of a conversation. It's easy to end up spending so much time online that you miss out on spending offline time with your friends – setting limits on how much time you spend online is important.

Safety

There are risks to participating in social media – just as there are risks in all aspects of life. Teach online safety to reduce those risks and let the people you support know what to do if they run into trouble online. Make sure people know what constitutes exploitive and harassing conduct and who to report such conduct to. Plan with them how they can check out questionable comments, requests, etc. with someone they trust without fear of getting in trouble. Here are some basic safety tips that should be a part of any teaching of social media safety:

- Don't accept friend requests from people you don't know
- Protect your password
- Use your privacy settings
- Keep private things private
- Be careful about clicking on links from sources you don't know
- Don't share your financial information online
- Remember that once a comment or picture is posted online, it's out there forever (and may be viewed by parents, employers, girlfriends/boyfriends and strangers)
- Report any harassing or abusive content to the social media provider, a trusted family member, friend or staff and/or to the police

Social Media and the Law

Some online activity is illegal and there are real consequences for those engaging in such activity. Ensure that people know what types of activities can get them into trouble on social media such as making threats, spreading hate, bullying, and looking at and/or creating child pornography. If someone has particular challenges that they are dealing with related to the law that social media may aggravate, then specific teaching and risk management strategies need to be developed with the person to ensure their safety and the safety of others. For example, if someone has a restraining order against them limiting their contact with a particular person, it will be important to ensure that they do not make a friend request to that person. It is equally important to ensure that people recognize when they are the victim of illegal online activity and what to do about it.

We have a responsibility to ensure safety and, in some cases, it may be necessary to provide some supervision online while we teach about safety, privacy, etiquette and the law. In such situations, it may be advisable to set up a monitoring system (with the person's knowledge and consent) where a staff or supervisor has access to the individual's social media accounts and conducts periodic checks to ensure that the his or her social media use is safe and legal. Set out a plan with the person ahead

of time for what you will do if the person makes mistakes. This plan may include additional teaching and creating visual cues or reminders, to temporary suspension of online access, up to reporting to police in instances where the law has been broken. Supervision can be faded as the person learns skills and demonstrates the capacity to self-monitor their online conduct.

There are great resources online for teaching and learning about social media – a quick search turns up a multitude of tips, tutorials and even full curriculums. These can be effective tools when paired with adaptations that make learning and remembering easier. One excellent site designed for teaching adults with developmental disabilities about online safety is www.icanbesafeonline.com a website created by Community Living BC.

There are many wonderful examples of social media enhancing the lives of people with intellectual disabilities, from the woman I passed in the hall today chuckling as her thumbs moved quickly over the tiny keyboard of her cell phone, explaining as I smiled at her that she was sharing a joke with her sister on Facebook, to the empowering impact of participating in online campaigns to garner rights and respect for people with disabilities. To get a sense of some of what is being done by people with intellectual disabilities using social media check out these links:

- <http://carlsvoice.com/home> a website featuring the writing and art of Carly, a young woman with autism, with links to her videos, Facebook profile, Twitter feed and more.
- <http://www.youtube.com/user/boymeetsworldfan1> the YouTube channel of a prolific blogger with Down syndrome talking about music, movies, school, sex and the issues she is passionate about.
- <https://www.facebook.com/EndtheWord> the Facebook page for the “Spread the Word to End the Word” campaign - a movement begun and maintained by youth with and without intellectual disabilities.
- <http://www.youtube.com/user/BCSelfAdvocacy?feature=mhee> a YouTube channel featuring a collection of videos by self advocates on a range of topics.
- <http://www.youtube.com/user/ponceman> a YouTube channel created by a young man with Down syndrome and his brother in which he plays a variety of characters in spoofs of popular television shows and raunchy comedy sketches. His videos are often offensive and cater to a style of humour perhaps best enjoyed by adolescent boys but they have gone viral and have spawned an acting career that most recently landed him a role in the movie *Looper* alongside Bruce Willis.

Conclusion

Social media offer exciting opportunities *and* come with certain risks. Supporting those we serve to take up those opportunities as they manage the risks requires that we teach – just like we teach people how to participate safely in many other social activities. When people become safe and savvy social media users, they stake a claim in the virtual community, asserting their right to participate and belong in this important social arena.

Editors: Dave Hingsburger, Vita Community Living Services and Angie Nethercott, North Community Network of Specialized Care, Hands TheFamilyHelpNetwork.ca

Answers to FAQ's about the Newsletter

- 1) The newsletter is intended to be widely distributed; you do not need permission to forward. You do need permission to publish in a newsletter or magazine.
- 2) You may subscribe by sending an email to dhingsburger@vitacls.org.
- 3) We are accepting submissions. Email article ideas to either the address above or to anethercott@handstfhn.ca
- 4) We welcome feedback on any of the articles that appear here.

