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The Nuts and Bolts of Health Care Project

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"I felt encouraged to express my ideas, and I noticed that they were taken into consideration, this made me more comfortable and made me feel like I belonged in this project, I can make change happen." Suela Sarci

Two years ago, we started a project called The Nuts and Bolts of Health Care together with researchers from the Centre for Addiction and Mental Health (CAMH), and the Health Care Access Research and Developmental Disabilities Program (H-CARDD) to determine how to help staff in our agency when it comes to health care and the people we support.

WHY we needed to do this was simple. H-CARDD research has shown us that adults with intellectual disabilities (ID) have more health problems, take many medications, are more likely to visit emergency departments, be hospitalized, and can stay in hospital longer than needed. Earlier H-CARDD work looked at how to help health care providers give better care, but what about people on the front line? As Direct Support Professionals (DSPs), we are there seeing things go wrong, and helping to make things go right, but we also need help to do our jobs better.

HOW to do this took some time for us to figure out, but it was something we worked on slowly and carefully together. We started by talking to the DSPs who work at Vita, along with the people we support in our agency, as well as by looking at the policies and procedures we already had about health and health care. Our team (comprised of staff from Vita, people from CAMH and H-CARDD) conducted interviews, held small group discussions, and also gave a survey to staff. To get people thinking and talking about health, we made a bingo game about health and health care that we played. Through all of these opportunities for personal story telling, gaps and needs were identified.

**Editors: Dave Hingsburger, M.Ed.
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Just like there is a science to help us test new drugs, or a science to figure out which people need health care the most, there is also a science of how to make changes happen. This is called “Implementation Science.” Without this kind of science, an agency like ours may try to make changes, implement things poorly, and then believe what we tried didn’t work when, in reality, we just did not implement the intervention properly. Learning about this implementation science framework was a “light bulb” moment for us. There were previous attempts in our agency at trying to make changes that had failed, never gotten off the ground, or fizzled out quickly, and now we understood why. Having this framework provided a structure around identifying what change was needed, how to make the change happen most effectively, and how to ensure that we could keep up the changes even after the project was over.

By talking to our staff, we learned a lot. Some of the hardest things were about waiting for visits, preparing for visits, and communicating with the health care providers, especially when it feels like they just do not want to listen. We learned that people do not like filling out mandatory forms. Keep things simple PLEASE. And if they had to choose who the best teachers would be, learning from other DSPs is the way to go.

One way we helped with training staff was through making two training videos using people from our agency. We showed real challenges and some potential solutions, trying to make the scenarios in the video relatable to other staff. The first video: ‘Everybody Wins: Preparing for a Doctor Visit’ provides ideas on how to prepare for a health care appointment. Some suggestions in the video include consulting with family or other more familiar DSPs, using the tool kit, having things prepared for a wait in the waiting room, as well as roleplaying what may occur at the visit beforehand. The second video: ‘The Game Changer: The Doctor Visit’ provides examples of how to effectively advocate for a person you are supporting during a medical exam, as well as how to assist a person you are supporting to have a clearer understanding of what is going to happen, or what is being recommended during a medical appointment.

You can watch the videos here: nutsandboltstools.com

One of the biggest changes we made in our agency was switching from our required health care visit form to two new forms for everyone in our agency. (All forms referred to in this article can be found in the Nuts and Bolts Took Kit at: nutsandboltstools.com)

The ‘About My Health’ form was created as a new required form to be completed for the people being supported at Vita Community Living Services. It is a tool designed to give health care professionals important health information that could be applied to any health care situation. This way, critical health care information can also be available during emergencies, and in the absence of a DSP who is very familiar with the person. We update the ‘About My Health’ form at least once a year and connect it to our yearly goal planning review process. DSPs have told us this document has helped them, especially when seeing a new health care professional, such as a specialist or a walk-in clinic. People with disabilities have said that they like that information about them, and what they like and dislike is available, especially when they can’t explain it themselves very well.

‘My Health Care Visit’ replaces the old form we used to complete at every health care visit. There is a part that gets filled out before, during, and after each visit. It prompts the DSP and person they are supporting to prepare for the visit and collect information about the problem to share at the visit. This includes helpful monitoring tools about problems like mood, bowel activities, and sleep. (All of these monitoring tools can be found in the Nuts and Bolts toolkit.) DSPs and people being supported told us that this worksheet has helped to make sure that symptoms and concerns are not forgotten during medical visits.

The health care provider then completes their section of the form to make sure their recommendations and follow-up is not forgotten or misunderstood. When the DSP and the person they are supporting return home following the visit, they fill out the final section and give some feedback on their experience, and what they might want to happen differently next time. The completion of the final section is also an excellent opportunity to make sure all follow-up details have been completed and communicated with the support team, such as booking blood work or sending in a new prescription. ‘My Health Care Visit’ provides an opportunity for the person being supported to have a better understanding of their health care by being included at each step of the process.

These two main tools are part of a bigger toolkit we designed together, which includes all sorts of other information for DSPs, including some explanations of common health care concerns, and clear definitions of commonly used health care terms. It includes tips for communication within the health care system, and tips to encourage better health self-advocacy. There is a section in the toolkit that provides plain language handouts for people with ID to help them understand and prepare for more challenging health care procedures like the mammogram or Pap test. There are also other links and resources identified in the toolkit for both DSPs and the people they support to get more information. We have printed copies of the toolkit in every home in our agency, and we also can find all of the tools on a website. This is because not everyone likes paper, and not everyone uses a computer.

Working on this project taught us about why it is important to look at what we do and not be afraid to ask questions about why we do it and how we could do it better. Just because something has been done a certain way for many years does not mean it has to stay that way. We came up with new ways to be health advocates and to do this side by side with the people we support. They now have more opportunities to be directly involved in their health care; they are more involved in preparing for these visits and deciding how to make them better. As DSPs, we are no longer speaking on behalf of the people we support; we are taking steps to encourage them to be their own health advocates. “Be my microphone, not my voice,” as Dave Hingsburger says.

Through this project, we also learned the importance of stepping outside of our comfort zones as DSPs. Change can only happen when we challenge ourselves to try things differently. Our experiences and knowledge are critical, and we need to share our stories for there to be an effective change.

Health Care Tips Learned

1. Preparation for health care visits is essential!
 - Have documents prepared with all the needed information identified.
 - Gather data about the problems before the visit to help give a full picture. Make sure there is always an opportunity for the person being supported to prepare for health care appointments based on their comfort level and support needs. Each person we support will need a different preparation process.
 - Have a copy of 'About My Health' available in the event of a health care emergency to prevent missing or forgotten information.
2. Bring forward observations of changes in health and support needs when you notice them. This direct observation of change is necessary for the people that are being supported to access health care in a useful and timely manner. We cannot wait for a health care provider to ask the question as it may never happen, and the health care issue may not get addressed.
3. Ask questions and look for information on health care issues that people are experiencing. Asking a pharmacist or health clinician for additional information can be a good start.
4. Take a team approach: DSPs and health care professionals both play an essential role, and health care cannot be effective if a team approach is not applied.
5. Involve the person with ID in their health care treatment from the beginning - this sets the stage for success. Present information in a way that supports their strengths and communication style. When they understand their health care and treatment plans, health care will be more effective.
6. Advocate for the person you support by making sure their voice, opinions and questions are heard and answered. Advocating is an essential skill that requires practice and development.
7. Take the time to develop a good working relationship with health care clinics. Health care providers need to know how the person you support communicates and their preferences. Establishing a respectful working relationship to support the needs of the person you are supporting sets the stage for effective health care.
8. Get familiar with the Nuts and Bolts of Health Care Tool Kit. Share these resources within your teams.
9. Watch the Nuts and Bolts of Health Care training videos with your team and start to brainstorm ideas of how to implement some of the strategies discussed.
- 10. Remember that change takes time; do not give up!**

Resources

National Implementation Research Network: <http://nirn.fpg.unc.edu/>

PSSP CAMH: <http://improvingsystems.ca/how-we-work/implementation-approaches>

<http://www.nutsandboltstools.com/>

<https://www.porticonetwork.ca/web/hcardd/site-map>

About the authors

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Answers to FAQ's about the journal

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