



CID-NY

Center for Independence
of the Disabled, NY

Center for Independence of the Disabled, New York (CIDNY)

Contact: Jess Powers, jpowers@cidny.org

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Using Stories to Motivate Action for your ILC

PREPARING CONSUMER STORIES FOR OUTREACH

Consumers may be willing to speak in public or to the media to illustrate an issue or concern. It is your responsibility to protect any consumer who is speaking for the organization as much as is possible. There are things you will not be able to control – how the media use the story, how the consumer reacts to the story being published or aired, and how people outside the organization react to the story.

Things you can control.

- It is your responsibility to help the consumer understand why their story is important, how you think it will be used, and how it will help the organization's goals.
- Always go through the story with the consumer. Make sure they are comfortable with their presentation. Help them understand why it is better to make two points rather than five.
- Get a biographical sketch. People will relate to the story better if they can relate to the person.
- Help the consumer with their language and expression, but be careful not to change their natural voice.
- Do a practice interview with the consumer – this will help them feel comfortable and will help you gauge whether the story will be effective.
- If the story is being used for testimony, try to have the person go to a hearing with you before they testify so they can see what the room and the procedures are like. You can also discuss what was successful testimony and what was not, and why.
- If someone is nervous or uncomfortable, always give them an "out." If they feel that they have to do something they do not want to do, they won't be effective spokespeople for your organization.
- Be clear about your inability to control how the media may use the story. Make sure that the consumer signs a release form.
- Be supportive. Do everything you can to help the consumer feel comfortable and that they are not alone. If possible, have them speak with someone else who has spoken out for the organization and had a positive experience. If possible, offer to go to the interview with the person.
- Be honest about your expectations and your reason for asking them to tell their story.



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Tips for Advocacy Interviews

1. Be a good listener: remember that the person you are interviewing is telling you an emotional story and is not necessarily savvy about keep to a few key points. You are the interviewer and editor. It will be up to you to put the story in context and to edit for points once the interview is over.
2. Tell the interviewee up front who you are, how you intend to use his/her story. If it is for testimony, advocacy and/or the media explain exactly what your intention is and why you want his/her story.
3. Be sensitive to the person's need for confidentiality. In most cases, if the story is to appear in printed form, you can offer to change names and personal information.
4. Be sure the person is willing to sign a release form or tell you in writing that it's ok to use their story.
5. Make sure you know what points you want to cover. Before the interview, establish two or three pieces of information that you want to be sure to cover in the interview.
6. Get a personal sketch of the person so that you can put them in context that others will understand, e.g., Joe is a 35-year-old New Yorker who was a bank executive, married with three children before he was diagnosed.
7. Don't worry if you get more information than you need. You can and should edit someone's story for the points needed in your advocacy efforts.
8. When editing, do not change the person's style of speech or word usage and do not put words in their mouths. Your story should reflect the person; it should be honest and real. You can add explanatory notes or narrative if you have to. If the person's words are unclear, it is better to go over something again and ask the person to explain. You can always say, "I'm not sure I understand what you mean..." and get the person to explain in different words.
9. When you have put the story together, have someone else from your organization read it and ask them to describe the main points of the story. If they are able to get the points you want and find the story compelling, then you've done your job. If they're getting a different message than you intend, take a second look at the story and see if rearranging the points or if putting the story in context will help.
10. Always keep your audience in mind. Remember that most people will "skim" these stories when they first read them. Make sure you capture their attention in the first paragraph, eliminate extraneous information and try to produce a tight, engaging story.



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Tips for individuals who want to tell their story

1. Decide on one or two points you would like to make with your story. Too many issues can make a story confusing and you may lose the attention of your audience.
2. Use your own voice. Tell your story as you would tell a friend. Don't try to sound like someone else. The power of your story is in your particular "voice."
3. Begin by telling people who you are. Let people know where you live, if you have a family, what you do or did for a living. This will help them understand your situation and how the issues affect you.
4. Tell your story in simple, clear and direct language. Don't use acronyms or jargon.
5. Speak as if you are speaking to a friend or colleague. After you've put your story together, tell it to a friend and ask them to summarize what they heard you say. If they don't understand the points you wanted to make, you will have to revise your story until your points are clear.
6. Keep your audience in mind. If you are doing a story for policy makers, you may want to emphasize different points than if you are speaking to others who are trying to understand your issues.
7. Don't try to be an expert on policy or technical details. Your expertise is your life experience – what happened and what continues to happen to you. If you are asked a question that you don't know the answer to, don't try to answer. Refer people to the organization you are working with or simply tell them that you don't know.
8. Make sure your goals match the goals of the organization you are working with. You will want to feel comfortable with the organization you are work with to make your story public. Don't be afraid to ask questions about the purposes and uses of the story you are telling.
9. If you are nervous or concerned about your presentation, get support from your colleagues. Others who are giving testimony or who are working with you can support you when you are ready to tell your story in public. You will find people in the organization you are working with who will stay with you through the process.
10. Stay active. Telling your story will help you understand how you can help in the efforts to obtain your goals. As you become more comfortable, you can help others tell their stories.



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Storytelling Exercise

Sean is a New Yorker with Cerebral Palsy. In order to maintain his physical health he requires ongoing physical therapy. Without the adequate amount of physical therapy Sean is less mobile; restricting his ability to walk or use his arms and hands. Right now, Sean can live on his own, shop for food, do his household chores and get out into the community. If he loses access to physical therapy, his physical condition will deteriorate, leaving him more dependent on other more expensive services, like personal assistance. "I can do things on my own, I can take care of myself. I don't understand why I can't get the help I need to stay that way." Sean wants to do as much as he can for as long as he can – he doesn't want to depend on a personal assistant to do everyday chores. He also doesn't understand why the system doesn't allow him to maintain his independence.

Anna is a woman with osteoporosis and injuries to her spine, hands, and feet. She is currently covered by Medicare as her primary insurance and Medicaid as secondary insurance. However, Medicare has very limited services for physical therapy and durable medical equipment which she depends on for braces for her back, neck, arms and orthotics for her feet. So for Anna, who needs ongoing physical therapy and replacements for worn out or broken braces and orthotics, limits set by Medicare do not meet her needs. At the same time, Medicaid will only pay for what is approved by Medicare.

Anna believes that Medicare's refusal to pay is not based on her physical condition or need, but is based on arbitrary limitations on services. "Who makes these decisions? What do they understand about what I need? I don't think they know what my condition is, I don't think they do understand – they just look at a chart to see how many PT visits I can have." Anna's services should be reviewed separately by Medicaid for medical necessity based on her medical provider's evaluation and not determined because of Medicare's limited services.

Jorge was a student with disabilities in Flushing High School. He remembers that he was integrated into a general education class when he was not ready and because he could not compete he eventually dropped out. Jorge feels that he was transferred to a general education class before he was ready because he never got proper evaluations.

For students like Jorge, timely and appropriate evaluations can mean the difference between school success and failure. Right now in New York, trained school psychologists can evaluate and monitor a student's progress – free to students and their families. For low-income families, these professionals can be critical for their children with disabilities. For students like Jorge, a misstep in evaluation can mean a missed education opportunity.



Sample Stories

Getting Health Coverage and Support to Go to Work

For Jaime*, a 27-year-old Latino with Asperger’s Syndrome, working with a CIDNY benefits counselor meant that for the first time, he was able to get health insurance coverage. A benefits eligibility check-up found that Jaime was eligible for Medicaid, so his counselor helped him fill out the online application form and send it in. Since Jaime would like to go to work, we were also able to help him understand how to apply for services under ACCES-VR, New York State’s adult career and continuing education services. Jaime is currently developing goals for his future and exploring his options to prepare for work.

Relieving Stress, Protecting His Children’s Health

Nahzir is a 49-year-old immigrant from Bangladesh with a heart condition, anxiety and depression. He has two young children and works two jobs to make ends meet. He made an appointment with a CIDNY counselor to see if he and his family qualified for any health coverage, but two weeks before his meeting, his wife unexpectedly passed away. He was very worried about childcare and feared losing work because of the added stress. Nahzir was unsure if he could receive public benefits because of his immigration status.

A CIDNY benefits counselor performed a benefits eligibility check-up and enrolled Nahzir and his children in Medicaid. The counselor referred him to his nearest HRA office for child care support. Nahzir was relieved to know his family’s medical needs would be taken care of and that he could receive child care help.



*All names have been changed.

[Image description: Photo of Gloria seated on walker with the statement: "Without Medicaid, I couldn't have this walker. I wouldn't be able to pay my rent. I would have to pay co-pays for all these specialists and medication."]



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Tools and Tips

www.grammarly.com

Free browser extension that checks for writing mistakes.

www.canva.com

Free tool to create infographics, visual social media posts, announcements, and more.

www.hemingwayapp.com

Free tool to simplify your writing by identifying complex sentences and word choices.

Action Alerts

- Should be a simple, clear call to action.

Blog Posts

Some guidelines for better blog writing:

- 2-3 sentences per paragraph
- Use keywords
- Use internal and external linking
- Write in a conversational tone using the active voice