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Nine Codes, Two Stories and One Message – A Deep Dive into the NADSP Code of Ethics

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I want to go skydiving.
 I want to get a tattoo.
 I want to get married.
 I want to go to California.
 I want to smoke pot.
 I want to get a driver's license.
 I want to go on a date with Brad Pitt.
 I want to go on a date with Angelina Jolie.
 I want to sleep in late and not go to work today.
 I want to color in my coloring book.
 I want you to leave me alone.

You may have heard these statements communicated from a person you support if you are a Direct Support Professional (DSP). All of them have a very central theme, even though, individually, they are different requests. All of these are very personal and desired intentions, some more obtainable and legal than others. Nonetheless, the ethical DSP will **never** discount a request of someone's deeply personal intentions. The ethical DSP will evaluate these requests in light of the National Alliance for Direct Support Professionals (NADSP) Code of Ethics and always put the person supported in front of the statement. The ethical practitioner will weigh the issues of safety, health, dignity of risk, and overall possibility with the person's desires and dreams. This becomes the craft of the DSP. It is an art form, a professional obligation and must always be done with great care and sensitivity.

We all have values and ideas/notions about the way things should be. We may work for provider agencies and/or people who hire us that have a specific set of rules and policies to follow. These may interfere with the process that is needed in order to abide by the spirit of person-centered practice. It is critical that Direct Support Professionals have a guide or a "map" to help inform them of their directions when assisting someone in making decisions and providing person-centered supports.

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Let's review the nine tenets of the National Alliance for Direct Support Professionals Code of Ethics:

1. **Person-Centered Supports:** As a DSP, my first allegiance is to the people I support; all other activities and functions flow from that allegiance.
2. **Promoting Physical and Emotional Well-Being:** As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize autonomy of the individuals receiving support, while being attentive and energetic in reducing their risk of harm.
3. **Integrity and Responsibility:** As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.
4. **Confidentiality:** As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.
5. **Justice, Fairness, and Equity:** As a DSP, I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights, and responsibilities of the people I support.
6. **Respect:** As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.
7. **Relationships:** As a DSP, I will assist the people I support to develop and maintain relationships.
8. **Self-Determination:** As a DSP, I will assist the people I support to direct the course of their own lives.
9. **Advocacy:** As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.

Collectively, these nine parts make up a validated and effective method for ensuring that DSPs do not inadvertently act unethically. What does that mean? All too often, Direct Support Professionals act from their intuition and “gut” reflexes. This can be dangerous in the context of supporting another person with their decisions about their life. Almost naturally, we want to offer our advice, opinions, experiences, and viewpoint when working with someone as they embark on a path of self-direction. Our opinions and advice may be helpful but cannot be the basis of our support relationship. DSPs must use each of the tenets of the code of ethics as they help others explore outcomes, consider possibilities, help assess risks, and give valid information as related to specific decisions or problems that may be experienced by a person supported.

The best way to illustrate how these “codes” truly work is to share stories that come from direct support practice. Over my years doing direct support, and supervising and teaching direct support professionals, I have been fortunate to experience situations where the implementation of the code of ethics helped in creating positive outcomes for people with disabilities.

The two stories you are about to read are true, but names and some details have been changed to honor confidentiality (one of the tenets of the code). Let's start:

Story One: *Driving My Life Away – Jimmy and Curtis*

Person-Centered Supports: As a DSP, my first allegiance is to the people I support; all other activities and functions flow from that allegiance.

Jimmy is a person with an intellectual disability who shares a home with three other men. Curtis has been a DSP in his home for 20 years and knows Jimmy fairly well. Jimmy is a man that lived in an institutional environment during the early years of his life. When he was 20, he moved from this institution to the provider agency where he met Curtis. This was 20 years ago. Now, Jimmy works in a part-time job at a fast-food restaurant and spends a lot of his time walking to town. His home is two miles from the town center.

Jimmy asked Curtis one day to help him obtain his driver's license. Jimmy is 40 years of age. He has a difficulty reading and writing but otherwise has no specific disabling conditions that would limit him from driving, at least any that Curtis could ascertain from his understanding of him and his medical/personal history.

In short time, Curtis realized that agency rules and policies may prohibit him from automatically taking Jimmy to the local Department of Motor Vehicles to get a driving manual and information about getting a learner's permit even though he thought it was a great idea, providing Jimmy with some new independence. Curtis also realized that he had to speak with his administrative/supervisory staff before any more preparations could take place in helping Curtis get his permit. Curtis may have the instinct to just take Jimmy to the DMV and let him see all the complicated steps to get ones driving permit/license. He may also have in the back of his mind that Jimmy may have difficulty navigating and understanding the driver's permit manual due to his limited reading and comprehension ability. Or he may let Jimmy drive down the street in his own personal car after traffic has subsided in the late afternoon one day. Curtis may want to do this for Jimmy to get a "feel" for being behind the wheel just like his father did with him before he got his learner's permit. Or Curtis may just dismiss Jimmy's request and "redirect" his conversation to another topic and not "encourage" this request because he just knows that he may be too intellectually disabled to understand the rules of the road and would be a danger on the highway.

The above possible reactions to Jimmy's request are ethically wrong. There may be threads of truth to all the possibilities above. However, it is ethics that must guide Curtis the DSP to look first at Jimmy's wishes, ideas, and dream. An ethical DSP will investigate, in-depth, with Jimmy his desire to suddenly want to have driving privileges and hopefully discover why and how he can get as close to this dream and wish as possible.

DSPs are frequently torn between the allegiance they must have for the people they support and the many, many influences and threats to that allegiance. Those threats include: rules of the provider/agency if there is a provider/agency in the person's life, laws, regulations, family member's wishes, safety concerns, weather conditions, and the list goes on and on...The important thing to remember is that, as one develops a sense of ethical person-centered

support, thinking and practice allegiance will become “total.” Total means all parts of that person whom you are supporting need to be considered, respected, and addressed in the situation presented. These parts include the facts about: where a person may live (in an agency, in a municipality with rules and laws, in someone’s home other than their own), what a person is perhaps challenged with physically or medically, what the guardianship issues might be for the person, if the person will lose dignity or become somehow endangered by the situation, and on and on. The key to being in allegiance with the person supported is to be holistic and open to all possibilities. Too often many different professionals in the human services are quick to “squash” dreams and wishes based on what their own perceptions may be of reality and life.

Story Two: “Could you please go get some supplies at the Administration Building?” – Rick and Cindy

Integrity and Responsibility: As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

Maybe this scenario sounds familiar to you: *I love my new iPhone. It has so many ‘apps’!! I can use it everywhere I go. I can use it even when I am sleeping. I surely can use it at work! It will be great. I can obtain all types of information that will help me support the people with whom I work. Only problem is that my organization has a policy that prohibits me from using my mobile phone when I am at work. I signed that I received the notice about the mobile phone policy at my orientation. Bummer. But I am always working alone and, in fact, who will know if I am using it to look up websites and other information for the people I support. It is for their benefit...I am thinking of the time that I used my phone to get movie times at the local theatre. I used my phone, got the movie times, and prices and took the guys to see Iron Man 2! If I did not have my phone to use, they may have lost out on the opportunity to see that movie!*

In this situation, a Direct Support Professional is tempted to break agency policy in order to benefit the quality of life for an individual(s) they support. As we all seemingly have mobile/cell phones these days, it seems like a silly formality to “not” use the phone on agency time. Especially, if we are using the phone to create options for the people we are supporting. However, to support the vitality and mission of the profession, we are obligated to follow agency practices and policies if we indeed work for one. A DSP shows very little respect for their profession if they break agency rules.

The story that we will use to illustrate **Integrity and Responsibility** is more serious than breaking an agency policy. This is a story about Rick the Direct Support Professional who witnesses a very difficult situation and decided to do the “right thing” and report the abuse of a person with an intellectual disability.

Rick was working with several people in a small group home where six adults lived. Rick was working with one other Direct Support Professional on the day of this terrible event. It was dinnertime, and Rick and the other DSP were assisting with dinner preparation and setting the table. The other DSP, Cindy, started to get loud and began to call one of the people she was

assisting some bad names. She said at one point, “Stop being a ret**d and chop the tomatoes the way I showed you!”

At this time, Rick remembered what he had learned in Abuse Prevention class, and he intervened. He took the person who Cindy had just spoken with and all the other people he was supporting who were in the kitchen and invited them all into the living room to watch TV immediately, saying he remembered that there was a great special report on the news he wanted everyone to watch. After that, he spoke with Cindy privately and asked her to go to the administration building of the agency to get some supplies they needed for an art project that they were working on that evening. Rick stretched the truth about this in order to be able to protect the other people he was supporting from Cindy’s abusive tone and words. He also was able to do his responsible action of calling the agency abuse prevention hotline to report Cindy’s actions.

Rick and Cindy were friendly and had a decent working relationship. Cindy was always a little “rough around the edges” when it came to her tone but, in this situation, Rick had to stop, report, and protect the people with whom he worked from continued abusive comments. Clearly, Cindy committed psychological abuse, and Rick met the ethical obligation of **integrity and responsibility** to stop it. He also followed agency and regulatory policies in order to address the terrible name-calling that was experienced that evening.

Unfortunately, this is the exact type of situation where a DSP will feel incredibly awkward. Even though it is obvious that name-calling and psychological abuse are unacceptable, it nonetheless becomes difficult to call out a co-worker and risk all the discomfort of reporting the situation to authorities, subsequently becoming involved in an investigative process.

Rick may have known that Cindy was experiencing personal problems and was going through a divorce. Rick also knew she was unhappy in her job and she spoke with him just the week prior about quitting and going to work in a retail job. It may have been tempting for Rick to take matters into his own hands. He may not have wanted to get administrative personnel involved, and could have turned his back on the circumstances, and just went on with the dinner plans as usual.

Rick did the right thing and was ethical in this situation. He did not try and “fix” the situation or “counsel” and re-direct Cindy on his own. Rick did what was responsible, and he characterized integrity by stopping abuse and reporting it immediately the way in which he was taught. Cindy admitted to the name calling, resigned, and sent an apology letter to the entire group home family. If Rick did not act with integrity and responsibility, he may have put even more people at risk and would not have helped Cindy leave a profession that demands only high ethics and standards of behavior and conduct.

These are only two stories that illustrate how complex the practice of direct support is. There are literally hundreds of thousands of interactions like these each and every day. Having no universal guide and method for addressing these ethical dilemmas is not negotiable. Thus, the NADSP Code of Ethics serves as the most practical and validated tool which DSPs can utilize.

One final message: All of us have a life perspective we bring to the table. When that interferes with the life perspective that is hopefully being developed by a person we support, we begin the process of being unethical. “The sky is the limit, and anything is possible,” must be the mantra for DSPs as they engage with the wonderful and often fantastic dreams of people with disabilities. Ironically, people with disabilities are over-protected and often limited by the very people who are paid to help them achieve, and dream, and live lives of distinction. Ethical DSPs will align with a person they support and then help that person make determinations about their decisions, balanced with a deep consideration of all the perspectives, and possible outcomes, and risks in every given situation. The NADSP Code of Ethics will be a welcome road map for DSPs and people they support in a person-centered world of direct support service.

The full text of the code is available free of charge at the NADSP website: www.nadsp.org

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About the author

John Raffaele is the Director of Educational Services at the National Alliance for Direct Support Professionals. His career spans over three decades, and those years have been spent teaching direct support professionals and the people they support, including those with IDD, at-risk youth, and people with chronic and terminal illnesses. John has also worked as a Director of Training and Education for a developmental disabilities service provider and taught at The State University at New Paltz, NY and for the City University of New York City. He founded his own international direct support professional consulting company in 2012 and has developed many exciting and informative training programs and helped propel the NADSP into national prominence. John became NADSP’s Director of Educational Services in December of 2016. John has educated tens of thousands of people in the NADSP Code of Ethics and Competencies and most recently, the NADSP Informed Decision Making curriculum and Frontline Supervisor Train the Trainer curriculum.

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