Living the Code of Ethics

In Support of People with Disabilities: A Primer



A joint publication of:





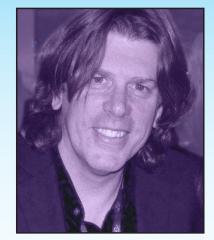
Dear Readers,

"Putting People First" is more than a slogan, a catchy tagline. It is the heart and soul of the New York State

Office for People with Developmental Disabilities (OPWDD), its purpose, its yardstick against which all other activities must be measured. It is also a challenge.

Each day, OPWDD supports scores of thousands of people with intellectual and developmental disabilities whose needs and desires are as multiple and varied as is their number. Central to this effort is a public and private sector direct support workforce whose nearly 100,000 members have diverse ethnic, racial and educational backgrounds and whose different life experiences shape what they bring to the job.

In 2011, when a series of New York Times articles depicted the horrible abuse, neglect and mistreatment of people with disabilities in New York State programs, OPWDD recognized the need to act.. While the articles



depicted the actions of a few bad actors, with a broad brush they painted a bleak picture of the vast majority of direct support professionals who do their complex jobs with great skill and dignity, every day – quite often without recognition or just compensation.

"It is critical that all direct support professionals, managers, clinicians and administrators share the same value of "Putting People First." If not, in the worst case scenario, abuse and neglect may occur; at best, the individuals they support may enjoy a safe and nice day, but miss opportunities for achieving a great and fulfilling life."

OPWDD recognized that it is critical for all direct support professionals, as well as managers, clinicians and administrators to share the same value of "Putting People First." If not, in the worst case scenario, abuse and neglect may occur; at best, the individuals they support may enjoy a safe and nice day, but miss opportunities for achieving a great and fulfilling life.

As such, in 2012, OPWDD adopted the Direct Support Professional Code of Ethics developed in 2001 by the National Alliance for Direct Support Professionals (NADSP). NADSP developed the Code in 2001 with the input of self-advocates, families, direct support professionals, clinicians and program administrators from across the country. It is intended to offer value-based guidance to direct support professionals as they support and walk in partnership with the individuals they support on their unique journey toward a life of opportunity, well being, freedom and contribution.

OPWDD recognized that simply "adopting" a Code of Ethics as a statewide policy would not be sufficient. The values embodied in the Code must be understood, embraced and lived by the direct support workforce. And, unlike other policy directives, which may be amenable to a "read and sign" training approach, the Code of Ethics required more to assure that it became a part of the workforce culture.

This book is merely an introduction to the Code of Ethics. We hope that you use it as a starting point that leads to deep discussion, debate and understanding of the values of being a direct support professional.

Joseph M. Macbeth Executive Director The National Alliance for Direct Support Professionals



As Bob Dylan said, "The times they are a changing." Across the nation, the role of staff who directly assist people with intellectual and other developmental disabilities is changing. And it's not just a title change. It reflects a fundamental transformation or shift in the culture of service delivery, or the ways in which services are provided.

This transformation is rooted in the realization that people with disabilities require and demand more than mere care and direct care staff. They seek support in achieving their life goals and staff who are knowledgeable about and committed to providing that support: Direct Support Professionals.

To support the basic principles of this transformation, the New York State Office of People with Developmental Disabilities has adopted the National Alliance of Direct Support Professionals' Code of Ethics. The OPWDD Region 2 Workforce Transformation Committee has dedicated this user friendly and engaging book to assist current and future direct support professionals to understand the Code of Ethics in theory and to embrace it in practice. Using real life examples, clear "do's and dont's" - and helpful suggestions, the Region 2 Committee intends for this book to be used frequently and freely in any and all of the following fashions;

- 1. To be read and discussed by all who are employed in supporting people with disabilities.
- 2. To be read by new employees within 30 days of hire, and regularly thereafter.
- 3. To be a resource available to all employees as needed.
- 4. To be discussed frequently and freely between frontline supervisors and direct support professionals, and all levels of management. The types of discussion will vary with particular positions; executive staff will focus on the coaching and supports they need to ensure ethical practices, while discussions at the point of interaction will generally focus more specifically on individual performance feedback.

"...to walk in partnership with the person, and those who love him or her, toward a life of opportunity, well-being, freedom and contribution."

> National Alliance for Direct Support Professionals, Code of Ethics, 2001.

To be used frequently and freely at team, house, department and agenwcy-wide meetings. As a new direct support professional, and perhaps even as a seasoned veteran, the expectations of the job can be overwhelming. Competing priorities, varying opinions, personal conflicts, and regulatory expectations create obstacles and barriers. Use this book to guide your thinking, define your path, to bring you confidence and peace of mind.

Start by reading the book; work every day on living its message; make ethical decisions; share the message; and, most of all, embrace it with the people you support and your colleagues!

On the Cover: The NADSP Code of Ethics Word Cloud was created by Dan Hermreck who is the Human Resources Training Coordinator for TARC in Topeka, Kansas. In addition to his duties at TARC, Dan also co-chairs the NADSP's Education, Training & Workforce Development Committee.

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PERSON CENTERED SUPPORTS

My first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Recognize that each person must direct his or her own life and support and that the unique social network, circumstances, personality, preferences, needs and gifts of each person I support must be the primary guide for the selection, structure and use of supports for that individual.
- Commit to person-centered supports as best practice.
- Provide advocacy when the needs of the system override those of the people I support, or when individual preferences, needs and gifts of each person I support are neglected for other reasons.
- Honor the personality, preferences, culture and gifts of people who cannot speak by seeking other ways of understanding them.

 Focus first on the person, understand that my role in direct supports will require flexibility, creativity and commitment.

Kenneth says: "I enjoy working in the kitchen when Chef's Express is preparing for a catering event. My DSP, Patti, sets up a counter just for me that makes it easier for me to assist with baking and being involved with catering. I feel honored that I am able to work in the kitchen and I'm glad we make desserts that people appreciate. I like thinking ahead about other ways I can serve. If there's any way I can help out, I'm there!"

Patti says: "Kenneth has had a desire to work inthe kitchen right from the moment he started receiving supports. We rearranged the counter space so it would be easier for him to bake and prepare other foods. Kenneth wanted to take a cake decorating class, so we helped him make arrangements to participate."





Person Centered Supports

DO:

- Know what "my first allegiance is to the person I support" really means.
- Provide factual information about the risks and responsibilities associated with choices.
- Be flexible, creative and committed to the people you support and always seek their opinions
- Provide advocacy with the person you support and help with their decision making.
- Always honor the personalities, preferences and cultures of the people you support.

DON'T:

- Make decisions, coerce or force any decisions for someone you support.
- Dismiss a person's wishes, dreams or goals or force your opinions or values upon anyone you support.
- Disrespect or treat anyone in a way that is less than dignified.
- Dictate what people should do or how to do things; help them understand what or how to do things.
- Be a "rogue" direct support professional and do ANYTHING without the knowledge of the person supported and their support team.

- Discuss the following words/phrases and what they mean as they relate to person centered supports:
 - Advocacy with People
 - Allegiance
 - Creativity
 - Respect
- Share a story about how you modeled person-centered supports when accessing the community with the person you support.



Promoting Physical and Emotional Well-Being

I am responsible for supporting the emotional, physical and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Develop a relationship with the people I support that is respectful, based on mutual trust, and that maintains professional boundaries.
- Assist the individuals I support to understand their options and the possible consequences of these options as they relate to their physical health and emotional well-being.
- Promote and protect the health, safety, and emotional well-being of an individual by assisting the person in preventing illness and avoiding unsafe activity.
 I will work with the individual and his or her support network to identify areas of risk and to create safeguards specific to these concerns.
- Know and respect the values of the people I support and facilitate their expression of choices related to those values.
- Challenge others, including support team members (e.g. doctors, nurses, therapists, co-workers, family members) to recognize and support the rights of individuals to make informed decisions even when these decisions involve personal risk.
- Be vigilant in identifying, discussing with others, and reporting any situation in which the individuals I support are at risk of abuse, neglect, exploitation or harm.
- Consistently address challenging behaviors proactively, respectfully, and by avoiding the use of aversive or deprivation intervention techniques.
- If these techniques are included in an approved support plan, I will work diligently to find alternatives and will advocate for the eventual elimination of these techniques from the person's plan.



Leonard told his direct support professionals that he felt he had gained too much weight. He asked them to help him to get more exercise. Along with the help of his staff, he looked into different exercise classes that were taking place in his community. Leonard got the help he needed to review the options available and then signup for most of the classes on his list.

His involvement in these classes led Leonard to begin walking three times a week, participate in Tae Kwon Do, swimming regularly at the YMCA pool and get involved in a "dancing to the oldies" class. He began to lose weight, feel healthier, and feel the benefits of improved self-esteem through improved self-image.



Promoting Physical and Emotional Well-Being

DO:

- Work with the person you support to implement practices that support good health.
- Assist in the understanding of options that may include risk and the nature of the risk.
- Assist in the understanding of illness prevention and the avoidance of unsafe activities/behaviors
- Always follow approved support plans to address challenging behaviors and respectfully challenge and advocate with the people you support when plans are unrealistic or not person-centered.
- Demonstrate your knowledge of the physical and emotional needs of the people you support with professional language and respect.

DON'T:

- Prevent informed risk taking after the person clearly understands options and his participation in the decision making process.
- Choose providers and professionals without understanding and consent of the person you support.
- Withhold accurate and factual information needed to help a person make informed choices.
- Assume that you know what is best in situations where there may be risk or perceived risk and dictate that; help the individual understand.
- Ignore that people you support may have spiritual and emotional needs.

- Discuss the following words/phrases and what they mean as they relate to supporting another person:
 - Choice
 - Impose your own values on another person's choice.
 - Risk
 - Well-Being
 - Professional
- Share a story about how as a Direct Support Professional, you have advocated with a person you support for their physical and emotional well-being.
- Can you give examples of situations when you helped an individual understand the
 health or safety consequences of an option they were considering? Or when you
 challenged team members to respect the rights of individuals to make informed
 decisions on health matters?



Integrity and Responsibility

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.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Be conscious of my own values and how they influence my professional decisions. Maintain competency in my profession through learning and ongoing communication with others.
- Assume responsibility and accountability for my decisions and actions.
- Actively seek advice and guidance on ethical issues from others as needed when making decisions.
- Recognize the importance of modeling valued behaviors to co-workers, persons receiving support, and the community at-large.

• Practice responsible work habits.

Joyce feels she has developed a good partnership with her direct support professional, Roxanne. It is a partnership built on a deep, mutual respect for one another. Joyce has worked with other direct support professionals in her past. She made the choice not to continue to work with these unreliable people because she felt they were not respectful enough of her and did not take the time in getting to know her well enough to do a good job. Joyce's direct support professional, Roxanne, describes Joyce as being very smart and aware. She described their getting to know each other as tough and at times she did not always do things in the way Joyce wanted them done. But Roxanne

> many years and who encouraged her to talk with Joyce and work things out one thing at a time. The time that was spent in discussing each area paid off as they have now built a wonderful working relationship.



Integrity and Responsibility

DO:

- Always use person centered language.
- Seek to understand and pay attention to the people you support in all situations.
- Follow rules, regulations and policies of the organizations for which you work and the laws of the state.
- Report and recognize abuse and neglect if you should witness it.
- Be an ambassador for the people you support and the organization for which you work.
- Use all the tenets of the code of ethics every day to ensure ethical practice.

DON'T:

- Violate confidentiality.
- Force a friendship on the people you support. You are a paid professional. If a friendship happens, that is even better.
- Make false promises.
- Dismiss the needs and desires of the people you support.
- Use your cell phone or text for personal use while in your direct support professional role.
- Accept the unethical practices of your coworkers.

- Please define the following words as they relate to supporting another person:
 - Respect
 - Integrity
 - Person-centered language
- Discuss times when you needed to seek advice and guidance on ethical issues when making decisions. What were the issues?



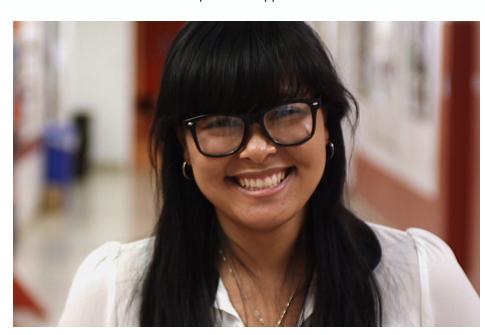
Confidentiality

I will safeguard and respect the confidentiality and privacy of the people I support.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Seek information directly from those I support regarding their wishes in how, when and with whom privileged information should be shared.
- Seek out a qualified individual who can help me clarify situations where the correct course of action is not clear.
- Recognize that confidentiality agreements with individuals are subject to state and agency regulations.
- Recognize that confidentiality agreements with individuals should be broken if there is imminent harm to others or to the person I support.

Tom: "I was in the grocery store when another Direct Support Professional from the home of a person I supported approached me and started telling me that the person was ill and in the hospital. I started feeling nervous because I knew that she shouldn't be sharing this person's private information like that. I got really close and said quietly that we shouldn't be talking about that person in public and asked her to call me at work. She realized that she had been out of line, apologized and called me the next day."



Stephanie: "I went to the doctor and the nurse called my name. She then asked my Direct Support Professional why I was being seen while we were still in the waiting room! My Direct Support **Professional looked** at me and didn't say a word until we were in the room. That made me happy!"



Confidentiality

DO:

- Protect and respect privacy in all areas of a person's life.
- Keep personal details about health and hygiene private.
- Share information only with the people who need to know that information for the individual's safety, health and well-being and who were approved by the individual, unless there is a imminent risk of harm.
- Learn about laws protecting health-care information.
- Ask permission before sharing information or stories about the people you support.
 Better yet, get them to share information and stories others want to know about the person.

DON'T:

- Talk about the people you support with your friends or family.
- Engage in gossip.
- Write or post information about or pictures of the people you support on your social media accounts.
- Assume that people will not care or be upset if you talk about them without their consent.

- Discuss the following words/phrases and what they mean as they relate to supporting another person:
 - Confidentiality
 - Privacy
 - Responsibility
 - Discretion
 - HIPAA
- Give an example of a time that you protected someone's privacy.
- Give an example of a time when you witnessed someone's privacy being violated. What did you do? What do you wish you had done?



Justice, Fairness and Equity

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.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Help the people I support use the opportunities and the resources of the community available to everyone.
- Help the individuals I support understand and express their rights and responsibilities.
- Understand the guardianship or other legal representation of individuals I support, and work in partnership with legal representatives interests are honored.

"As a Direct Support Professional, I worked at a group home in Central New York for a few years. There were people I supported who had just turned 18 and they were asked if they would like to register to vote. They were very excited to be able to pursue this right. A team of professionals helped set up a

learning

session with a local agency that provided support to people with learning and developmental disabilities. They employed a teacher who taught us all about the voting process. The teacher came to the home where they young voters lived, explained the process, what to expect, and provided information on the different parties and candidates as well.

to assure that the individual's preferences and Leading up to election day, the Direct Support Professionals working in this home helped encourage this group of individuals to get as much information as they could about the candidates through TV and newspapers so they were prepared to make informed choices. When election day came, each of the individuals were very excited and each successfully cast their vote. It was a day of satisfaction and accomplishment for each of these people and I am proud I was part of it."





Justice, Fairness and Equity

DO:

- Treat everyone with dignity and respect.
- Treat everyone fairly.
- Advocate when you see someone being treated unfairly.
- Encourage, assist and support people to advocate for themselves and exercise their rights.
- Ensure that others treat the people you support fairly.

DON'T:

- Let people be disrespectful.
- Discourage people from standing up for their rights.
- Discourage people from having big dreams.
- Put your values and beliefs before the people you support.
- Treat people you support as if they were children that need to be cared for.

- Have you ever heard a Direct Support Professional say "I treat individuals I support like my own child or family"? If so, what does that mean to you?
- Have you ever been in a situation where an individual you support was being treated unfairly? If so, how did you respond?
- What could you have done differently in that situation?



Respect

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.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Seek to understand the individuals I support today in the context of their personal history, their social and family networks, and their hopes and dreams for the future.
- Honor the choices and preferences of the people I support.
- Protect the privacy of the people I support.
- Uphold the human rights of the people I support.
- Interact with the people I support in a respectful manner.
- Recognize and respect the cultural context (e.g. religion, sexual orientation, ethnicity, socio-economic class) of the person supported and his/her social network.
- Provide opportunities and supports that help the individuals I support be viewed with respect and as integral members of their communities.

Bob shares that he has lived most of his life with people with disabilities. Aides thought that they were better than he, and he was not allowed to speak for himself. His Direct Support Professional, Mark, says that based on the stories Bob has told him, the aides should have been arrested. He experienced abuse and disrespect.

Bob says "But I found my voice. I fired those who did not respect me. I now hire my own staff. I take care of my own money. I go to the bank and get out what I need. I go out on my own in the local neighborhood and play cards and hang out with people in my building. The old place was on a highway. Now I can get out on my own in a safe neighborhood." Mark says that he respects Bob, helps him to set up "call a bus", decide what to eat, if he wants to get out or stay home. Mark says "I am so proud of him. I am surprised at what he can do, that I originally thought I would have to do for him. He has impressed me more than once." He is proud of Bob's patience.





Respect

DO:

- Listen.
- Support friendships and relationships and assist people to develop and maintain new relationships and friendships.
- Understand that everyone has different and valuable skills and abilities.
- Recognize that people we support are a natural part of their communities (sometimes with our help and support).

DON'T:

- Speak for or over people you support.
- Make decisions for people you support.
- Push your personal beliefs upon people you support or coworkers.
- Disrespect choice made by people you support because they are different from yours.

- Tell how you have provided respectful support to someone who utilizes a wheelchair or other assistive device.
- Give an example of a time you witnessed someone being disrespectful.
- Tell how you have demonstrated respect for other people.
- Tell what it means to you to be respectful of the people you support.



Relationships

I will assist the people I support to develop and maintain relationships.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Advocate with the people I support when they do not have access to opportunities and education to facilitate building and maintaining relationships.
- Assure that people have the opportunity to make informed choices in safely expressing their sexuality.
- Recognize the importance of relationships and proactively facilitate relationships between the people I support, their family and friends.
- Separate my own personal beliefs and expectations regarding relationships (including sexual relationships) from those desired by the people I support based on their personal preferences. If I am unable to separate my own beliefs/preferences in a given situation, I will actively remove myself from the situation.
- Refrain from expressing negative views, harsh judgments, and stereotyping of people close to the individuals I support.

Creating memories on vacation; joining social groups, inviting family members over for dinner; these are all the traditional ways to foster and maintain relationships and Direct Support Professionals are instrumental in assisting the individuals they support to achieve these activities. An individual you support may be a mother. She might also have grand-children.

As a Direct Support Professional you may end up with a very crucial role in helping a person to maintain such relationships. Whether it be arranging transportation to ensuring visits to occur as the individual requests, to facilitating communication between family members to accept choices.

YOU make a difference. As we all know, family relationships have their ups and downs, but as a Direct Support Professional you have a critical position that can help

shape these relationships for the individuals you support so that the ups outnumber the downs.





Relationships

DO:

- Facilitate natural supports. Assess and discover what those natural support are for the people you support.
- Provide opportunities for inclusion.
- Provide education about opportunities in the community.
- Actively seek to connect people to new experiences.

DON'T:

- Cross professional boundaries.
- Put your personal feelings and values before those of the people you support.
- Judge the people you support or their choice of friends.
- Let your personal life interfere with your professional direct support obligations.

- Discuss relationships as they relate to supporting another person.
- Tell about a time that you advocated with an individual while in the community.
- Tell about a time that you assisted an individual with an issue that they were having in an intimate relationship.
- Tell a story of how you supported an individual with interacting with family or friends.
- Tell about a time you had to put your personal beliefs about relationships aside because they were different from person you were supporting.



Self Determination

I will assist the person I support to direct the course of their own life.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Work in partnership with others to support individuals in leading self-directed lives.
- Honor the individual's right to assume risk in an informed manner.
- Recognize that each individual has potential for lifelong learning and growth.

Karen says "I develop and follow the path that I want for employment, learning, recreation, faith, home and community. I choose the people who I want to invite into my life. I interview and hire my staff. I choose my career and I direct my staff on how to support my career goals. I am in control of whom I share my home. I am in control of my life."

"I went to a nearby neighborhood and had a full charge on my wheelchair, but the GPS took me up a big hill. Eventually the wheelchair tripped a circuit. People came to help me and called the fire department. I called my direct support professional who quietly came with my van, just smiled and shook her head. I smiled back, as it was all in a day's activities and we were on our way. Self-determination is about living life and supporting me with my ups and downs."

"In my opinion, promoting self-determination is one of the most important tenets of the Code of Ethics. It is precisely what a Direct Support Professional uses to be ethical."





Self Determination

DO:

- Respect the authority and dignity of the people you support.
- Learn to assist as well as let the people you support trouble shoot situations so they may learn from those situations and problems.
- Support people in learning from their mistakes.
- Be patient and let people speak and communicate for themselves.

DON'T:

- Contradict the people you support.
- Be an authoritarian or "know it all".
- Be someone who cannot accept the values of another.

- Tell how you have helped someone reach either a professional or personal goal.
- Tell how you would support someone you work for if they were being treated disrespectfully in the community.
- Give an example of how you would assist an individual you supported to become a valued member of the their community.
- What does self-determination mean to you?



Advocacy

I will advocate with the people I support for justice, inclusion and full community participation.

AS A DIRECT SUPPORT PROFESSIONAL I WILL:

- Support individuals to speak for themselves in all matters where my assistance is needed.
- Represent the best interests of people who cannot speak for themselves by finding alternative ways of understanding their needs, including gathering information from others who represent their best interests.
- Advocate for laws, policies, and supports that promote justice and inclusion for people with disabilities and other groups who have been disempowered.
- Promote human, legal, and civil rights of all people and assist others to understand these rights.
- Recognize that those who victimize people with disabilities either criminally or civilly must be held accountable for their actions.
- Find additional advocacy services when those that I provide are not sufficient.
- Consult with people I trust when I am unsure of the appropriate course of action in my advocacy efforts.

We arrived in Albany in time to attend the SANYS U: Leadership Training workshop. We were also able to go to two more interesting workshops after lunch. One was an update on the People First Waiver. We heard enthusiastic, encouraging people tell us about speaking up for ourselves and following our dreams. We were able to get answers to questions about getting the services that we need.

We stayed overnight at the Marriott in shared rooms, which was fun. We were amazed to learn that one member of our group had never before stayed in a hotel! On the morning after the conference, we participated in a march by region. It was so uplifting to see over 200 people marching to demonstrate against cuts to Medicaid and promote awareness!

It is vital that we continue to network and teach each other how to be strong advocates as we struggle to keep funding going to help us meet our needs and live self-determined lives. Education received through attendance at these annual state-wide, regional, and local SANYS conferences is truly priceless! We MUST go again next year!"

"We left very early in the morning in two big vans and headed to Albany. A few of us had never beenhat far away from Central New York. At the Marriott, it was so exciting to see so many people in one place at one time focused on self-advocacy and our needs.



Advocacy

DO:

- Demonstrate respect for the differences of opinion but always advocate with a person you support to help get their opinion heard.
- Promote decisions to be heard and considered.
- Promote rights of people with disabilities
- Take action when rights are denied above all else do this WITH the people you support.

DON'T:

- Tell people you support what they want or what they need; ask them.
- Make chocies for the people you support.
- Assure you know what is best.
- Infringe upon the personal rights of the people you support.

- Describe what advocacy means to you.
- What does it feel like to have someone advocate for you, as opposed to advocating with you?
- Tell about a situation when you advocated with a person with a disability. What was the outcome?



THANK YOU!

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