

Insulliance Mentor Manual (last updated 10/13/21)

This manual has been created for your reference. It includes tips that are vital to your success as a mentor with the Insulliance program. It is important that you take the time to read and digest the material here, regardless of the extent of your volunteer history with children with diabetes. Because you are volunteering for a program that takes place in a hospital, it may feel natural to you to share your own management tips with other PWDs. However, you must be very careful to avoid turning the conversation to yourself. Some of the individuals who ask to meet with you may be newly diagnosed. These cases will require extra care and caution. This mentor manual will provide extra information for these situations. Thank you for volunteering and making a difference in the diabetes community. If you have any questions or would like to go over and reflect on how a visit has gone, please feel free to contact Kaavian directly.

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INSULLIANCE MENTOR EXPECTATIONS AND GUIDELINES

Our Philosophy: Insulliance was developed with a philosophy that emphasizes working *with* diabetes, coexisting in the dynamic relationship that accompanies the disease. Insulliance aims to improve the lives of children faced with the challenges and struggles of life with diabetes by helping them to understand their personal diabetes story. We aim to open dialogue and create partnerships that have the capacity to build and strengthen the diabetes community as a whole. We are optimistic that Insulliance will continue to be effective in self empowering children, and teens to improve their diabetes management. Insulliance mentors will be leaders, setting examples for participants, as they help to normalize the condition for youth and battle the influence of stigmas associated with diabetes and disability.

Goals of Insulliance Program:

- To provide information and support to CHRCO patients and their families
- To review resources in more detail and assist with referrals.
- Concrete assistance (setting attainable goals with patients, etc.)

1. Time commitment: 2-4 hours/week, 8-16 hours/month

- In-Person Mentors will receive volunteer hours through CHRCO (sign-in sheet located in the Volunteer Office, third floor of main hospital) and also through the Insulliance program (sign in on contact sheet – name of patient you met with, duration of meeting, and a sentence commenting on the visit).
- Online Mentors will receive volunteer hours through our Google Calendar.
- Should a mentor be unable to make it to his/her shift, he/she is expected to inform Kaavian Shariati (9258189335) 24 hours prior to the scheduled shift, and is encouraged to find an alternate mentor to fill in, if necessary.

2. Mentor Shifts: Outpatient and Inpatient

- Endocrinology Clinic Referrals (outpatient): T/Th/ Friday (am only)
 - Morning shift: 9:30AM – 12:30 PM
 - Afternoon shift: 1:30PM – 4:30 PM
 - Leadership will contact mentor at beginning of week, and coordinate mentor shift assignment based on both mentor availability and clinic demand
- On call Referrals (inpatient): M/T/W/Th
 - 5PM – 7PM
 - Mentors will be alerted 24 hours in advance if there is a patient to be seen.

3. Meeting Protocol:

- Introduce yourself
- Explain your role
- Start where the family/patient is...
- Offer resources specific to the needs and interests of the PWD and family

4. Keep in mind:

- You are “cheerleaders”
 - Find and focus on strengths and accomplishments
 - Remember to be personable, and outgoing
- **Maintain good boundaries**



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- Know the difference between compassion and “connection through misery”
- Share your experience when necessary to assist the mentee
- Do NOT give medical advice
- Try not to “hog” the conversations
- Be aware that thoughts and feelings are communicated verbally and non-verbally
- Provide reassurance and support with a non-threatening, and non-judgmental attitude while avoiding comparisons.
- Practice active listening techniques:
 - Ask open-ended questions such as “I don’t think I understand” or “Can you talk about what you mean by...?”
 - Make sure your specific questions are to clarify what the other person wants to communicate, not what you want them to say
 - Allow time for silence and contemplation, calm silence can build trust, try to feel comfortable with that silence
 - Listen within the framework of the other person’s purpose and needs; sometimes, light social conversation may be leading to a concern
 - More about this in the Mentor manual on page 9

5. Be alert to red flags:

- Anything that interferes with the patients health medically and emotionally, for example:
 - “I’ve stopped taking insulin”
 - “I have given up”
 - “I don’t care what happens”
 - Any extreme emotional reactions
 - Any reports of someone being hurt or abused
- Contact Kaavian about any concerns, questions, or red flags
- Please remember to respect the confidentiality of the patient and family

6. Contact information:

- Kaavian Shariati: kaavian.shariati@ucsf.edu, (925) 818-9335
- Olivia Panzarella: olivia.panzarella@gmail.com, (925) 984-8282

Interacting with Kids in the Hospital

- **Talk at eye level:** Often it is frightening to have people towering over children (Kneel on the floor, sit in a chair, etc. Get on their level!)
- **Introduce yourself to patient and families:** Upon entering each room, introduce yourself and your role clearly and simply
- **Give children real choices:** When possible, let child choose the type of activity, resources to use, etc
- **Support the family relationship:** Include family members in conversations and decision making
- **Respect the patient's right to privacy and personal space:** Ask before moving into their space; not all patients may welcome another stranger interaction
- **Remember not all kids are raised the same:** Our kids come from different backgrounds and cultures. Respect individuality and diversity
- **Smile:** Be friendly and welcoming; be an active listener

Interacting with Kids Virtually

- **Share your screen, and/or use the Whiteboard feature to discuss concepts.**
- **Introduce yourself to patient and families:** Upon entering the room, introduce yourself and your role clearly and simply. Make sure your video is on!
- **Give children real choices:** When possible, let child choose the type of activity, resources to use, etc
- **Support the family relationship:** Include family members in conversations and decision making
- **Respect the patient's right to privacy and personal space:** Ask before moving into their space; not all patients may welcome another stranger interaction
- **Remember not all kids are raised the same:** Our kids come from different backgrounds and cultures. Respect individuality and diversity
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Building Motivation

An important part of your job as a mentor is to build up motivation in your mentees. This can be tricky, but you have diabetes, so you are fortunate enough to understand what works and doesn't work. Your goal is to show them that being self-motivated is a 'cool' thing. Try not to ask the questions that sound like nagging. Find new ways to ask the questions that used to bother you. Before meeting with a mentee, think of all the things you wish you had been asked when you were an adolescent, and try them out. Remember that this is a brand new program, and there may be trial and error before.

Rolling with resistance

Expect that some kids and possibly even parents that you meet with may not engage with you. They may be resistant to the idea of talking to another person during a visit (at a children's hospital visit, they speak with a lot of people). Knowing how to deal with "resistance" on the part of the participant is a skill you will learn very well with practice.

When faced with a resistant mentee, try changing up your method and avoid confronting them or attempting to 'get them back on track'. Instead roll with the direction the mentee is heading. This technique will often bring the mentee back to a balanced or opposite perspective. It could also help them to see their resistance. Later in the conversation, you can bring attention to the thing that sparked the resistance, which would also function as a learning moment for them.

Clarifying personal values

This skill involves you asking the mentee to identify and discuss values/attributes important to them perhaps even beyond the scope of diabetes. Let them know you want to get to know them. This process can lead to an exploration of whether or not there is a connection between current self-management behaviors and personal values.

Understanding Empowerment

The feeling of empowerment may vary per person. It is important to keep in mind and understand that diabetes is a patient-managed disease. There are many reasons for less than awesome management, as you all have experienced. A part of empowerment is digging into and discovering what drives a lack of effort or ability to manage. If you are meeting with a child who is newly diagnosed, this step is very important. You will want to emphasize the fact that diabetes is not an isolating, end of the world, disease. You can use some of the operational principles of empowerment below to help shape your own reflections and thoughts about how to best communicate your personal.

Principles of Empowerment

Diabetes is a patient-managed disease. This means that a person with diabetes has the power to self-manage and, thus, makes decisions about his/her health. A person with diabetes who makes an **informed** decision can be said to have made an **empowered** decision.

The person with diabetes has the right and responsibility to make informed decisions about their own care. If they select the changes they want to make, then they may be more likely to stay motivated to make and sustain those changes. This does not mean that you should tell youth to make changes to their own management plan! Please do not do that! BUT it does mean that if THEY choose to journal or count carbs, then they are more likely to follow through than if their doctors and or parents ask them to. You can help youth by sharing with them “the day you decided to take care of yourself for YOU.” It may help them think about their own choices and feel empowered in doing so.

Empowerment does not mean that you do everything perfectly to manage your diabetes or everything that your health care providers recommend. Rather, it means that you have weighed the personal costs and benefits of various options to make **informed choices** that are consistent with the realities of your life, priorities and values.

Facilitating Behavior Change.

Empowerment-based communication includes focusing on feelings and goals and problem exploration.

Eliciting “Change Talk”

This skill involves creating an environment in which the participant makes “self-motivating” statements about reasons for change, imagines making the change, and builds his or her own confidence to make changes.

Goal Setting

Creating quick goals with your mentee may help them to begin searching for personal goals. You can tell them to find a goal that inspires them, one that is measurable, relevant, and time-specific. It is VERY important that you encourage them to think about a goal that is attainable. That means they should select a goal that is achievable. Inspire them to think about their own goals and tell them it is up to them to decide when they want to make an empowered decision to begin their journey to reach the goal.



Problem-solving

This process involves identifying the problem, generating a list of possible solutions, exploring the benefits and drawbacks of each solution, and selecting the most suitable solution.

Healthy Coping

Every day we are faced with experiences that catch us off-guard and force us to confront aspects of ourselves that we may find inconvenient, undesirable, and often painful. Whether it is the loss of a loved one, a bad test grade, a blood sugar result, or getting stuck in traffic, we all have our own methods of coping. These methods can be influenced by one's culture, religion, upbringing, friends and family, genetics, and life experiences. It is of utmost importance that you understand your mentees words and actions as the product of their learned coping strategies. It should be your goal to understand your mentee's personality, but also to help them identify, examine, and uncover the many ways in which they cope with diabetes. Understanding the feelings that drive action can lead to a deeper understanding and acceptance of one's life circumstances.

We hope that both you and your mentee can learn and be inspired by the resilience of the human spirit-leading you to understand and establish new methods of coping that you can apply to your own personal struggles. This program is heavily reliant on the development of trust and friendship. Creating this safe space will allow us to both learn from and teach one another.

The Power of Language

Below is a list of words and phrases that are less charged when it comes to diabetes care. Adults who grew up with the disease compiled this list. Using the terms, phrases, and questions here may help a child develop a sense of empowerment toward their diabetes.

1. Would you rather be called a **'person with diabetes'** or *'diabetic'*?
2. When asking how many times a day someone tests their blood sugar say **'check'** instead of *'test'*.
3. *Avoid reacting* to the numbers you see and especially to an A1C, ask your MA's and nurses to do the same.
4. Emphasize how the child/teen **feels** rather than numbers.
5. Instead of saying *'diabetes control'*, say **'diabetes management'**
6. *Avoid passing judgment* about management, either positive or negative. Even if you only offer **positive reinforcement** and remain neutral in other times, the child/teen may notice a difference and feel negativity through the absence that positive reinforcement. ***
7. **Celebrate:**
 - *Offer high fives for making it to the doctor's office.
 - *Offer high fives for working the full time job of diabetes.
1. Ask about friends at school and how they react when a low happens (this could be a reason why a child doesn't take enough insulin, they are afraid their friends wont know how to respond).
2. Avoid alluding to diabetes as a *'battle'*, try the term **'challenge'** instead.
3. Ask a child/teen to explain a typical reason why they might have a high blood sugar.
4. Refrain from calling a child with diabetes a *'patient'* to their face. A *'patient'* to them may be equivalent to *'sick person'*, which may create or reinforce feelings of being a victim of diabetes.
5. Avoid asking things like *'do you want to be doing better'*, and instead ask **'do you think there is anything you could do differently so that you might start feeling better?'**

Active Listening

“There’s no me in Active Listening”! ← That isn’t entirely true. But, in active listening we try to understand what the other person is thinking, feeling, wanting and what the message means. It is listening for intent and content. Active listening is sensitive listening. A major part of this process requires you to be active in checking your understanding before responding with your own new idea or message. We ask open-ended questions or restate our understanding of their message and reflect it back to the sender for verification and to allow the sender to build on what he/she had said. This feedback process is what distinguishes active listening and makes it effective. Central to active listening is asking open-ended questions and making reflections.

Asking open-ended questions.

Open-ended questions are questions we ask that cannot be answered by “yes” or “no” or a one-word answer. An open-ended question helps open the door for the person to continue talking and exploring what they are trying to say.

- *Close-ended question:* Are you angry about having diabetes?
- *Open-ended question:* What are your thoughts about having diabetes?
- *Close-ended question:* Do you inspect your feet every day?
- *Open-ended question:* Tell me about your foot care routine.

Making reflections.

This skill involves stating in your own words what you understand the speaker has said. This skill serves to check your own understanding and to encourage the speaker to continue explaining his/her point of view. You can reflect back the content, thoughts, or feelings that the speaker conveys. However, it is most helpful to focus on the feelings and to clarify your perception of the issues, so the speaker knows you are listening and understanding his/her emotions.

- *Participant:* Every time I leave the house, I have to remember to bring my insulin pen, my meter, and some hard candy just in case I have a low. Having diabetes is a full-time job.
- *Mentor:* It sounds like you are feeling overwhelmed with all the responsibilities you have because of your diabetes

Things to remember:

- Clarify before you put in your two-cents
- Before you share, make sure they feel understood. Practice validation when possible.
- Try to infer where THEY want the conversation to go
- Listen for passive or overt attempts to bring up certain topics (possible taboo topics)

Active Listening Role Playing

Below, there are two scenarios to evaluate

A: Example of less-helpful listening

Mentor A: “How did you feel or react when you found out you had diabetes?”

Participant: When I found out I had diabetes I just cried and cried.

Mentor A: I would have gone to another doctor to get a second opinion.

Participant: Responds naturally to question to continue the conversation.

B: Example of helpful active listening

Mentor B: “How did you feel or react when you found out you had diabetes?”

Participant: When I found out I had diabetes I just cried and cried.

Mentor B: It sounds like you were very upset.

Participant: Responds naturally to question to continue the conversation.

Participant: When you are the participant, your job is to talk about your real feelings. Do NOT pretend to be someone else, make up a problem or give answers that are not authentic for you. The conversation needs to be meaningful enough so that it provides a real opportunity to explore your thoughts about it. During the role-play your job is to respond authentically to what the peer leader says. Be yourself and do not try to act like another person because this is not fair to the peer Leader. The peer Leader needs the opportunity to work with genuine responses, not matter what they may be.

Mentor: When you are acting as the peer leader your job is to try and help the participant discuss and explore their thoughts and talk about their feelings and emotions regarding the issue. Your primary role is to **practice active listening and ask open-ended questions**. Do not offer observations, or medical advice. Your goal is to be as helpful to the participant as possible.

T1D Community Resources

Finding support outside of the clinic is a great tool to have within one's diabetes care arsenal. However, not all patients will be receptive to expanding their diabetes community, and it is important to gauge their interest and response to your recommendations or suggestions. Below are just a few of the many T1D resources that we recommend familiarizing yourself with. There will also be a list in clinic that you may find helpful to review, both prior to mentoring, as well as with the patient.

- **Brave Buddies** – active Yahoo Group and email listserve for Bay Area parents of T1D kids.
- **Carb DM** - groups for parents, kids, teens, educational events and more. Primarily based in Peninsula/Silicon Valley with some activities in the East Bay and San Francisco. www.carbdm.org
- **DASH Camp** – “Diabetes and Sports Health” Camp for T1D kids in the Bay Area. www.dashcamp.org
- **Diabetes Hands Foundation (DHF)** – the organization behind TuDiabetes, an online social networking community for people with all types of diabetes. www.tudiabetes.org
- **Diabetes Youth Families (DYF)** – provides camps and year-round programs for T1D kids/teens and their families. www.dyf.org
- **Children’s Diabetes Foundation of the North Bay** – provides support network, events and an annual retreat
- **JDRF Online Resources** –
 - JDRF Bay Area hosts a comprehensive website with resources and information for anyone with T1D.
 - Social Hub is an online calendar of T1 diabetes-related social events, groups and activities hosted by community organizations, clinics, health care professionals and other individuals.
 - The Online Diabetes Support Team (ODST) is available round-the-clock to answer questions and provide email support within 48 hours.

 - Type1Nation - a vibrant social network created especially for and by people with type 1 diabetes and their loved ones.