

# Using Photovoice with a Vulnerable Population to Influence Policy Change

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# Today's Presentation

- \* Purpose:

The purpose of this presentation is to increase nurses' awareness of their role in promoting health and wellness among marginalized populations.

- \* Objectives:

- \* 1. Identify 3 facilitators & 3 barriers to health and wellness for adults with intellectual and developmental disabilities.
- \* 2. Describe 1 methodology effective for collecting research data when working with a marginalized population.

# Literature Review

- \* Deinstitutionalization ≠ Emancipation (freedom)
- \* Increased health disparities
  - \* Cardiovascular disease
  - \* Obesity
  - \* Vision
  - \* Dental
- \* Health promotion through targeted activities
- \* Health entangled with concept of disability
- \* Where is the voice?

# Research Questions

1. What do adults with I/DD, living in the community perceive as facilitators and barriers to health and wellness?

2. What are the direct support professionals' perceptions about facilitators and barriers to health and wellness for adults with I/DD?

# Methodology

- \* The setting
- \* Participant selection
  - \* purposive selection
  - \* 11 adults with I/DD (27-62 years, 6 females, 5 males)
  - \* 9 direct support professionals
- \* Photovoice & Photo elicitation → participants
- \* Focus group → direct support professionals

# Photovoice

- \* Individuals take photos of situations or topics and share the meaning of the photo.
- \* 3 main goals of Photovoice (Wang & Burris, 1994; Wang & Burris, 1997):
  - \* Reflection on reality for an individual
  - \* Stimulate dialogue
  - \* Inform policy makers

# Photo Elicitation

- \* Introducing photos into an interview process.
- \* Goal of photo elicitation (Clark-Ibáñez, 2004) :
  - \* Encourage conversation between participant and researcher.
  - \* Expanding the dimension of communication.

# Major Themes Shared by Participants

- \* 6 facilitator themes:
  - \* Relationships
  - \* Knowledge of health promotion
  - \* Nature as health promotion
  - \* Emotional health
  - \* Pride
  - \* Spirituality
- \* 3 barrier themes:
  - \* Relationships
  - \* Negative influences
  - \* Boredom



## Relationships



The reason why I took that one, is because I am really a Yankee fan, that's mostly [it], I am really a sports fan, I love the Yankees and the NY Giants. [I took this because] it has to do with activities, I go out and go to a game and things, and I go out and meet new people and stuff like that. That is why.

## Relationships



She likes to play, we have a fan in my room and then we have one in the dining room. She sits there and stares at it, like, when it is going around. And I think that is so cute, how they can sit like this, and hitting you in the face with her tail. She don't [sic] want me to leave. She cries a lot. I pick her up and rock her.

# Knowledge



*“This is healthy, actually very healthy, because it is fruit and you should have fruit, fruit is something you should have.”*

Tell me more about when you go shopping, do you make your own list

*“No, I don’t make a list, I basically get whatever I need for that week”*

How do you decide what to make or cook?

*“I decide what I want to make that weekend. I don’t make a list. I only have \$45/week for food”*

You took a picture of peaches, how often do you eat fruit?

*“Not often it depends on what I feel that week. There are things I can’t eat, like apples and oranges because of acid, I have reflux [reflux]. I can eat bananas, peaches, pears and carrots, things like that. “*

# Knowledge



Oh - she is drinking water, it is healthy water, definitely during the summer. Definitely during the summer days, but it is always good to drink basically 6, 8 oz glasses of water/day.

## Pride



I work at Price Chopper. I worked there for 11 years, next year it will be 12 years!!!! I get ready for work, I comb my hair, and I shave, I put on my pants, no, my shirt first and then my pants. I got black shoes that I wear. I got a brand new hat too. You know what it says? 'Price Chopper - #1'. I am good at it, I put the toilet paper and the tissues all together. I put the eggs on top. Then I fold the piece of paper and put it in the bag. The paper goes in the bag.

# Negative Influences



It is hard, very hard. You know like, we go out and we get coffee. And I don't mind that. It is just when they turn around and they, these guys, usually in the morning we go there, and we have, well a breakfast wrap. You know it's hard, even though they can eat it and I can't, but what I am trying to do is [talk to] Lisa [nutritionist]. If I could eat it and let her know that I am going to have it, so that way I can substitute my insulin. I am trying really hard not to do what I am doing now, which is really bad. I should not be cheating like this.

## Negative Influences



“It is really hard for you to be healthy because one gets dunkin’ donuts all the time, unless you are getting something that is good for you. But sometimes it is not, Dunkin’ Donuts is not good for you. She didn’t have nothing that day, in there that was healthy for you.

You could have something better to have. You know, coffee is not good for you either. But at least it could be good to have besides a Dunkin’ Donut thing. You could have juice, you could have milk, you could have that or you could have something NOT from Dunkin’ Donuts.”

## Nature/Boredom



That's all the flowers we had outside the house. I took that, I did. I like being outside a lot, I don't like being inside the house, it is bored in the house, sitting around. I like being outside. Next year, we are going to have a garden, I am going to be doing that again, I am going to take picture of that, again, next year.



# Summary and Policy Implications

- \* Photovoice was an effective methodology.
- \* Facilitators/Barriers were similar & consistent.
- \* Authentic voice of participants has contributed to a growing body of knowledge around health and wellness.
- \* Choice is not a one size fits all concept.
- \* Participants were able to assert themselves, and describe their daily experiences.
- \* Life long learners, life long teachers vs rules & regulations

### Introduction

Eleven individuals supported by this agency participated in a research study focusing on benefits and barriers to their health.

During the study, they used cameras to take photographs of things that helped or made it more challenging to be healthy. Afterwards, they also described the meaning of the photos.

These are some of their photographs and stories which they have selected to share.....





# Policy Implications

- \* Contributes to the authentic voice of participants with disabilities to a small but growing body of knowledge.
- \* Appropriate and sustainable conditions that support health and wellness rather than targeted disease and health issues.
- \* Continue to design research that includes authentic voice of participants.
- \* Fiscal/social policy issues concerning costs of eating healthy, cost of health promotion in relation to health restoration.

# Final Thought

- \* The view of health among the participants in this study had more to do with day-to-day social activities and experiences, hobbies & interests, emotional states, and having energy, than with physical symptoms of chronic conditions or their disability.

# Thank you

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