Welcome!

Please tour the mobile, photovoice micro-gallery

Use the cards handed to you at the door to write reflections, themes, critiques and questions that you’d like to share.

INCLUSIVE EVALUATION

Reflections: What do you think or feel when viewing these data?

Questions: What do you want to know about photovoice or inclusive evaluation when you see these photographs and quotes?
Planning & Implementing Inclusive Evaluation

Collaborating with Co-Evaluators with Intellectual & Developmental Disabilities

Kenneth Kelty, Student & UP Participant
Seb Prohn, M.S.
University Participant Program, Western Carolina University
Proposed Agenda

- Photovoice micro gallery tour
- Introductions & key terms
- Presentation goals
- Reasons to conduct inclusive evaluation
- Strategies and examples of inclusive evaluation
- Evaluation results and outcomes (in progress)
- Questions- ANY TIME
Kenneth Kelty

• **Interests**
  - traveling and experiencing different cultures, photography of sites, and friends, fashion, going to museums.

• **Post- college goals**
  - live in an apartment or townhouse with a friend, travel to Europe, Asia, and other US States, live in a big house in New York City, be successful and get married.

• **Strengths**
  - Memory - Autism helps because I am able to remember events that have happened in more detail then most people.
  - Motivation - Autism and an Intellectual disability helps to motivate me to work hard.
University Participant Program
Western Carolina University

- Provide a two year, on-campus living and learning experience for college-aged individuals with intellectual disabilities

- The only federal model demonstration site in NC

<table>
<thead>
<tr>
<th>Year</th>
<th># of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>2</td>
</tr>
<tr>
<td>2010</td>
<td>4</td>
</tr>
<tr>
<td>2011</td>
<td>8</td>
</tr>
<tr>
<td>2012</td>
<td>7</td>
</tr>
<tr>
<td>2013</td>
<td>8</td>
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</tbody>
</table>
The UP Program and Me

- Social inclusion: The UP Program has been a great new experience for me because it’s helped me get involved and meet new people.
  - International Studies Club
  - Asian Student Association
  - The Diversity Committee
  - The Delta Sigma Phi fraternity

- Academic Inclusion
  At WCU I do take the same classes as my non-UP peers
  ✓ Global issues
  ✓ Facebook Generation Marketing
  ✓ Career Exploration
  ✓ Foundations of Communications

- Vocational Inclusion
  - On campus I do work with enTOURage where I give campus tours 2 days a week. I also work with creative services.
What do UP Participants do at WCU?

- Live on campus and experience college life with same age peers
- Attend WCU classes
- Participate in social events and activities
- Create and follow an individual plan (IPCP) to guide personal development for post-UP success
- Work on and off WCU’s campus
Participants’ Campus Jobs

- Athletic Department
- University Housing
- Campus Recreation Center
- Catamount Clothing and Gift Store
- EnTOURage
- Facilities Management
- Greenhouse
- Hunter Library
- Kneedler Child Development Center
- Student Mail Services
- Cullowhee Kids Preschool at Cullowhee United
- Severe disabilities grant
Ghost Stories?

• Campus facilities are inclusive.
• Classes are inclusive.
• Campus workplaces are inclusive.
• Research question: Are participants socially included or just physically included?
• Social inclusion
  • Lasting & reciprocal relationships; valued social roles and membership in a larger group or community
Who can answer the inclusion question?

<table>
<thead>
<tr>
<th>Natural Supports</th>
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<tbody>
<tr>
<td>Quant.</td>
</tr>
<tr>
<td>Perceptions of participants'</td>
</tr>
<tr>
<td>- Social Support</td>
</tr>
<tr>
<td>- Sense of Community</td>
</tr>
<tr>
<td>- Loneliness</td>
</tr>
<tr>
<td>Qual.</td>
</tr>
<tr>
<td>- Open ended questions</td>
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<tr>
<td>- Focus group</td>
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<tr>
<td>- Explicate surveys</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>UP Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUAL.</td>
</tr>
<tr>
<td>- Photography</td>
</tr>
<tr>
<td>- Semi-structured interviews</td>
</tr>
<tr>
<td>Photovoice</td>
</tr>
<tr>
<td>Analysis &amp; Interpretation</td>
</tr>
</tbody>
</table>

Interpretation
Survey results inform focus group and focus group results
Compare & contrast results
Interpretation of [quant + qual] + QUAL
How can social inclusion questions be answered?

- **PHOTOVOICE**
- **Recording** experiences via photography
- Photographs **promote** dialogue
- Participants **convey** experiences, interests & concerns to broader audience.

“visual representations both depend on and produce social inclusions and exclusions”
Rose, 2007
Key Terms

• **Intellectual disability (ID)**
  - Limitations in cognitive ability and adaptive behavior
  - Not a permanent defective condition within the individual; spectrum of ‘fit’ within environments and contexts
  - Limiting or disabling environments present more challenges
Key Terms

• ‘Participants’
  • Transition aged (18-24 yrs.) college students with ID participating in an inclusive postsecondary education experience.
Key Terms

Natural Supports

• Paid or unpaid college students who are about the same age as participants who intervene and support as necessary to facilitate inclusive participation in dorm life, course work, social and recreational activities
• Friend, mentor, and role model
• Support, not a crutch
Why it is important for students with ID to participate in the Evaluation process?
When people with ID are not listened to…

- We become more isolated
- We have fewer opportunities-like college
- Our social development is delayed
- Nothing is changed for the better
- Others do not understand what having a disability or autism is like.
- It gives OTHER people the power to control our lives and make decisions for us.
If Doctors Made My Life Decisions…

• When I was 3 in a half I was diagnosed with Autism and my parents were told by a good doctor that I would never talk or be able to do a lot.

• What if we had listened to him?
Setting Higher Expectations

• Early intervention, speech therapy, my family, and my community helped me develop and grow.

• Now I am doing all sorts of neat stuff
  • going to College
  • being in a fraternity
  • researching
  • speaking at conferences
  • going out with my friends.

• I am free to make my own decisions and be in control of my destiny.
### D.C.- Two Trips, Two Stories

#### 5th Grade

**Fear / not understand my differences**

- When I was in the 5th grade my school did not want to take me with my peers to DC.
- My mom had to challenge the schools so I could take the trip with my peers.

#### College

**Celebrating & valuing my differences**

- In college my opinions and research are valued
- I am asked to come to D.C. to share my evaluation and raise awareness for inclusive evaluation
## Barriers to Accessible Research

<table>
<thead>
<tr>
<th>Reported by people with ID (Heller, Pederson, &amp; Miller, 1996)</th>
<th>Researcher observations (Paiewonsky, Love, &amp; Prohn, 2012)</th>
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</thead>
<tbody>
<tr>
<td>• Lack of training in the research processes and procedures</td>
<td>• Researchers rarely reduce complexity when explaining research content or purpose</td>
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<tr>
<td>• Insufficient support</td>
<td>• Method modifications are limited</td>
</tr>
<tr>
<td>• A sense that researchers did not really listen to what they wanted</td>
<td>• Limited transportation options to engage in research activities that are designed to be participatory and ongoing</td>
</tr>
<tr>
<td>Benefits of Collaborative Evaluation Students with ID</td>
<td></td>
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<tr>
<td>------------------------------------------------------</td>
<td></td>
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<tr>
<td>• Improve self-identity and confidence (Booth &amp; Booth, 2003)</td>
<td></td>
</tr>
<tr>
<td>• Capacity/skill building; sense of ownership (Jurkowski, 2008)</td>
<td></td>
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<tr>
<td>• Build capacity for advocacy (Kramer, Kramer, Garcia-Iriarte, Hammel, 2011)</td>
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<tr>
<td>• Involvement and self-determination influence one another (Wehmeyer, et al., 2011)</td>
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<tr>
<td>• Stories are a resource- access to resources</td>
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Piloting
Pilot: Lessons Learned

• ‘Typical’ college experiences: going to class, doing homework, living in residence halls, attending sporting events and working on campus.

• Captured places where they were spatially included.

• Described the importance of FRIENDS.

• Don’t limit photography to digital cameras. Can be unnatural. Outsider status.
How long will this evaluation project last?
The project will last at longest through the spring 2013 school semester.

What are the benefits and risks of partnering in this evaluation project?
If you want printed copies you will receive copies of your photographs. You will learn about doing research in the college environment. You will be able to tell your own stories related to your photographs, express your feelings and opinions that will help make the UP Program and WCU best support present and future UP participants. The main risk is that someone will recognize you in the photographs.

Will I be paid for participating in this evaluation project?
You will not be paid for participating in this evaluation project.
Evaluation Training
# Learning Vocabulary

<table>
<thead>
<tr>
<th>Research</th>
<th>Evaluation</th>
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<tbody>
<tr>
<td>• To make or uncover knowledge we</td>
<td>• Listen feedback</td>
</tr>
<tr>
<td>• Ask questions</td>
<td>• Make sense of the research gathered</td>
</tr>
<tr>
<td>• Collect facts</td>
<td>• Making something, like programs or colleges, better</td>
</tr>
<tr>
<td>• Analyze information</td>
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</table>
How to tell one’s story and help add detail

• Looking at the picture and explaining what it means (SHOWED process)

• Explain emotions felt when taking and looking at pictures.

• Explaining how the picture can educate others

• Is the picture bright enough and close enough?

• What is the location?
## Action vs. Posed shots

### Action shot
- Moving around or walking.
- Running around or anything movement related.
- Subject not looking at camera.

### Posed shot
- Standing with a group of people with your arms around them.
- Looking at the camera.
# Objects vs. Subjects

## Objects
- Statue or thing that looks interesting to you.
- Site seeing
- Not alive or not identified

## Subjects
- People, friends, and family.
- The people who are the focus of your photo.
- Must sign consent form.
Staying Safe

Safe photos

• Getting permission.
• Staying polite.
• Excitement you see and feel looking back at the photo.

Unsafe photos

• Someone does not want their photo taken.
• Something in the picture might put them in danger.
• It’s against their culture or religion to be in a picture.
Photo consent form

• Before using a picture of any person have them sign a consent form; respect their wishes whether they sign yes or no.

• Inform the person that if they choose their real name will be kept anonymous.

• Subjects and photographers both sign the form to keep their promises to each other.
RESULTS
Social Activities
Participants’: Reoccurring Perceptions

- Making & having friends
- Supports: bonding and bridging
- Feeling connected & similar to peers
- Technology- stay involved & maintain relationships
- Giving back- volunteering, fundraising, educating, helping others
- Acknowledging competence
- Friendships grow via repeated interaction & investment (social, political, cultural capitals)
# Participants’ Advice & Suggestions

<table>
<thead>
<tr>
<th>ADVICE</th>
<th>SUGGESTIONS for Program</th>
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<tbody>
<tr>
<td>• Join clubs &amp; interest groups</td>
<td>• More independence</td>
</tr>
<tr>
<td>• Work hard then play hard</td>
<td>• Fewer top-down activities</td>
</tr>
<tr>
<td>• Stay active</td>
<td>• More scheduling flexibility</td>
</tr>
<tr>
<td></td>
<td>• Differentiating independent leisure</td>
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</tbody>
</table>
Supports: Reoccurring Perceptions

- Managing multiple roles: friend/family & support
- Supports are catalysts to social network expansion
- Scheduling creates barriers to spontaneous social interaction and activity participation
- Better support training to avoid unnatural interactions, i.e., ‘baby talk’ and ‘watered down’/ manufactured/convenient inclusion
- Reciprocal relationships: feeling less judged; support as therapeutic; program as support network, family & mission;
- Inclusion is a learning process: individual, organizational (GREEK LIFE!), institutional levels
Perceived Quality of Participant Inclusion

“How do natural supports evaluate UP participants’ social inclusion in the campus community?”

- Participants have supportive Friendships: M=4.54; N=68
- Participants are perceived as members of the campus community: M=4.47; N=62
- Participants have connections with people on campus: M=4.57; N=62
There was a significant, negative correlation between natural supports’ perceptions of UP participant loneliness and perceptions that UP participants had supportive friends ($r = -0.47$, $p<0.001$), strong emotional connections ($r = -0.27$, $p<0.05$) and frequent positive social interactions ($r = -0.40$, $p<0.001$).
OUTCOMES
# Outcomes: Changes in scheduled time

<table>
<thead>
<tr>
<th>Non-scheduled time</th>
<th>Control over my own schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>• During the end of the day or weekends, Leisure planning on my own.</td>
<td>• On weekends, it’s great to have the control over what I do for social events with friends</td>
</tr>
<tr>
<td>• Having the freedom to choose what I do with my own time.</td>
<td>• More flexibility; not so structured.</td>
</tr>
<tr>
<td></td>
<td>• If there is an activity or something else getting to change what I do and call the person to explain</td>
</tr>
</tbody>
</table>
Using Research Skills for WCU Creative Services

- I am the Deputy logo photographer and I go around campus take pictures of logos that are out of date.

- I work there 2 days a week and also do some office work as well or express ideas for something new.

- I really like my job because I like taking pictures of sites and with friends.
Program Outcome

• Constructed better methods for measuring and facilitating ‘independence’

• Created student privacy memorandum of understanding

• Modify support and service learning training- focus on rapport building & assisting as needed
Improving Photovoice

- Improve photo release form training
- SHOWeD was helpful but limiting, yielded similar responses
- Adapt for those with communication barriers
- Increase student dissemination - AEA!
Recommendations

• Teach participants the research process
• Develop easy to understand approaches to seek consent
• Use multiple and intensive data collection strategies
• Presume participants’ credibility
• Use plain language
• Produce dissemination materials that are universally accessible and meaningful
QUESTIONS?
Contact

Kenneth Kelty
WCU Student & UP Participant
kpkelty1@catamount.wcu.edu

Seb Prohn
Academic Director & Outreach Coordinator
UP Program
Western Carolina University
smprohn@email.wcu.edu
828.227.2712