CONNECT 2O/8O™

Inclusive planning for the whole community

PEOPLE WITH DISABILITIES:
Community Engagement Report

for
The City of Rochester
Emergency Management Division
Rochester, Minnesota

Program and report developed by

inclusion=solutions

PEOPLE WITH DISABILITIES: Community Engagement Report

August 8, 2014

For

City of Rochester
Hazard Mitigation Assistance Planning

By

Patrick Hughes
Mike Baskin
Inclusion Solutions
2000 Greenleaf Street, Suite 3
Evanston, Illinois 60201
847-869-2500
phughes@inclusionsolutions.com
mbaskin@inclusionsolutions.com
www.inclusionsolutions.com

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INTRODUCTION

The City of Rochester's Division of Emergency Management is writing an All Hazard Mitigation Plan. The appropriate agencies and professional staff have been engaged to write this plan.

Essential to the creation of a "living" plan is to engage in the planning process the community of citizens who would be most vulnerable in cases of emergency: people with access and functional needs.

This engagement process was attempted in early 2013 by inviting members of disability organizations for a series of meetings hosted by Parks and Recreation in Rochester. The meetings included advocacy groups and representatives from housing organizations. Three meetings were held with limited success towards the goal of building a plan that includes the views and input of people with disabilities.
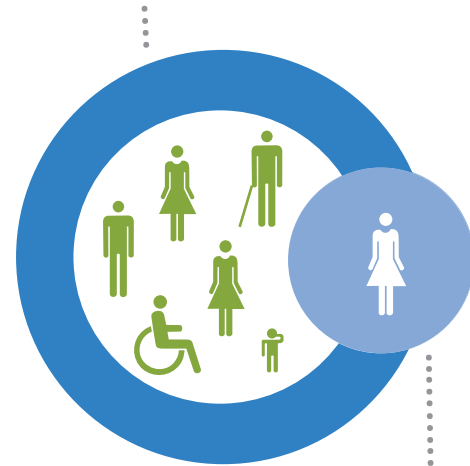
Inclusion Solutions was therefore contracted by the City of Rochester to implement their CONNECT 20/80 program as part of the Preparedness (Planning) phase of the Four Phases of Emergency Management. The program set out to accomplish the following:

1. Identify the Functional Needs Support Services (FNSS) population and key organizations / people to include in the planning process.
2. Lead and facilitate introductory meetings that support communication "in perpetuity".
3. Report on key findings and processes for the final Hazard Mitigation Plan for the City of Rochester.

This report will set out what was learned from our meetings with citizens with access and functional needs in Rochester.

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IDENTIFY ORGANIZATIONS

IDENTIFY KEY PEOPLE ("Captains")

FOUR PHASES OF EMERGENCY MANAGEMENT

RESPONSE

READINESS

RESPONSE   RECOVERY

EMERGENCY MANAGEMENT VISION
Effective Emergency Response
Disaster Resilient Community
Build Community Partnerships

Planning
Training
Exercising
PREPAREDNESS

PREVENTION/ MITIGATION
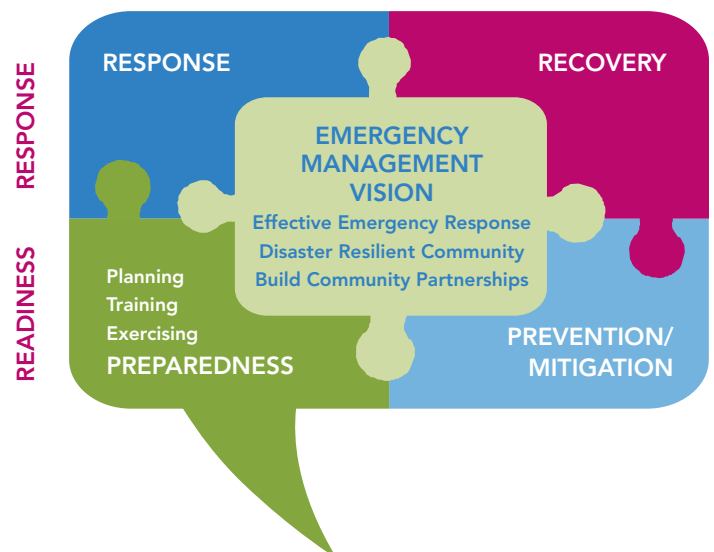
HIGH LEVEL SUMMARY OF FINDINGS

"We're all the same…but different."

1. The key ingredient to our methodology is to meet people with disabilities and their caregivers **where they live their lives.** We recommend continuing with this model to access contribution from the FNSS population.

2. Meetings were conducted with groups of people with like disabilities and similar situations. We recommend continuing with this model to access contribution from the FNSS population.

3. "Captains" were identified for each group. We recommend sustaining relationships with these captains to gain input on the best use of dollars and resources in planning, training, and exercising for preparedness.

4. Most people with disabilities want to contribute. There was little defensiveness, unreasonableness, or anger expressed in our meetings.

5. Listening is the most powerful tool in gaining access to contribution and gaining "buy-in" (FEMA Task 3) from the FNSS population. Therefore, creating an environment where "listening is made easy" will increase contribution.

6. Public hearings tend to limit contribution of ideas and experiences to a self-selected group. We found this method not to be an effective way to learn what needs to be learned and to test ideas with citizens.

7. One person does not speak for all with the same disability. For this reason, finding the right "captain" (who recognizes this and solicits other points of view in the community) is essential.

"We're all the same… but different."

8. Think of meetings where important information is exchanged as taking place at the kitchen table. The most important and honest conversations in life take place at home, around a table, where everyone feels safe and respected. We duplicated this vision as much as possible — and recommend continuing to replicate it.

9. Communication with the deaf community needs to be rethought. Participants in our meeting with the deaf community clearly stated that much is lost by writing things down; real communication (at the kitchen table) requires an ASL interpreter.

10. Witnessing genuine dialogue with those in the disability community is a compelling agent for change. We were told by many participants that the power of these meetings went beyond what was learned from citizens with disabilities: seeing the impact of these meetings on colleagues sharpened and made more permanent what was heard and felt.

BACKGROUND

All communities have people with disabilities — on average, 20% of the population. It is the responsibility of Emergency Management to develop an All Hazard Mitigation Plan that takes into account the differing needs of those with access and functional needs — no easy task!

For example:

- What is the best way to communicate to a blind person the direction from which a storm is coming?
- What is the best way to alert a person with spinal cord injury at night, when he or she doesn't have immediate access to the wheelchair, of an impending hazard?
- What is the best way to communicate at the scene of an accident with a person who is deaf, and no ASL interpreter is available?

FEMA states that "process is as important as the plan itself" as "*the plan is only as good as the process and people involved in its development.*" (emphasis added) (p. 1–2, Local Mitigation Planning Handbook, March 2013). For this reason, FEMA advocates the "Whole Community" approach to developing an All Hazard Mitigation Plan. The Whole Community approach is described as follows on their website:

> When the community is engaged in an **authentic dialogue**, it becomes empowered to identify its needs and the existing resources that may be used to address them. Collectively, we can determine the best ways to organize and strengthen community assets, capacities, and interests. This allows us, as a nation, to expand our reach and deliver services more efficiently and cost effectively to build, sustain, and improve our capability to prepare for, protect against, respond to, recover from, and mitigate all hazards. (emphasis added) (http://www.fema.gov/whole-community)

A First Try

This engagement process was attempted in early 2013 by inviting members of disability organizations for a series of meetings hosted by Parks and Recreation in Rochester. The meetings included advocacy groups and representatives from housing organizations. Three meetings were held with limited success towards the goal of building a plan that includes the views and input of

"I discovered more gatekeepers than helpers. "

people with disabilities.

Ken Jones, the City of Rochester's Emergency Manager, described it this way:

> In 2004, I conducted a "special populations" tabletop exercise at the behest of my coworker. She was planning a large full-scale exercise, and wanted to include disability groups as a lead to the big event. The tabletop went well and opened my eyes to [a group that we as planners, often miss].
>
> …A few years later…Spurred on by FEMA to include the whole community, I wanted to reach out to disability and multi-cultural groups. Not sure where to start, I asked for help. I discovered more gatekeepers than helpers. *Why do you need to reach out? I have groups I work with, but can't share my mailing list. Let me get back with you.*
>
> Eight months later…I sat down with a disabilities group and a few representatives of other groups…. I explained emergency management, why planning (vs. plans) were important; how the unique needs of their groups should be served in a disaster; why recovery needed to include considerations for people [with access and functional needs].
>
> After the first meeting, they decided to recruit more attendees to hear my message. The next month was a recap of my first presentation. 'I want to help you' was my plea…. [However, the attendees] were not

people who had disabilities. They provided services to clients with disabilities. I gave them samples of plans, links to resources, and instructions for how to respond. I was ready for the next step, and at our next meeting…only a few…came back. Satisfied with what I provided, there was no reason to meet again, they told me.

I [concluded that I was in front of] the wrong audience, [and reasoned that I] needed to find the right way to make my case. The next opportunity came with the application for a Hazard Mitigation grant…as the new FEMA guidelines had just been released and stressed Outreach as an early phase of development.

It was the charge of Inclusion Solutions to develop a plan for outreach (as described by FEMA) and create the basis for continuing relationships with those in the community with access and functional needs. Ken Jones put it this way: "At the outset, I asked Inclusion Solutions for one thing: meaningful relationships that will be sustainable with [people with disabilities]…not their agents."

The methodology which nurtured this dialogue is described in the next section beginning on page 7.

Why 20/80?

Approximately twenty percent of a typical community has a disability, according to the U.S. Census Bureau.[1] Traditional planning focuses on the "general population" (the 80%), and then making special accommodations for those with "special needs" (the 20%). This 20% can be harder to reach and harder to understand — and so emergency plans often account for people with disabilities by referencing statistics, rather than engaging with real people and understanding the diversity of the local disability community.

We believe that by seeking out and engaging first with the "20%" — those often vulnerable in emergencies — and preparing for their needs, emergency managers will be better able to create a plan that serves the needs of the Whole Community. It's not "80+20" — it's "20+80".

The 20/80 Snapshot
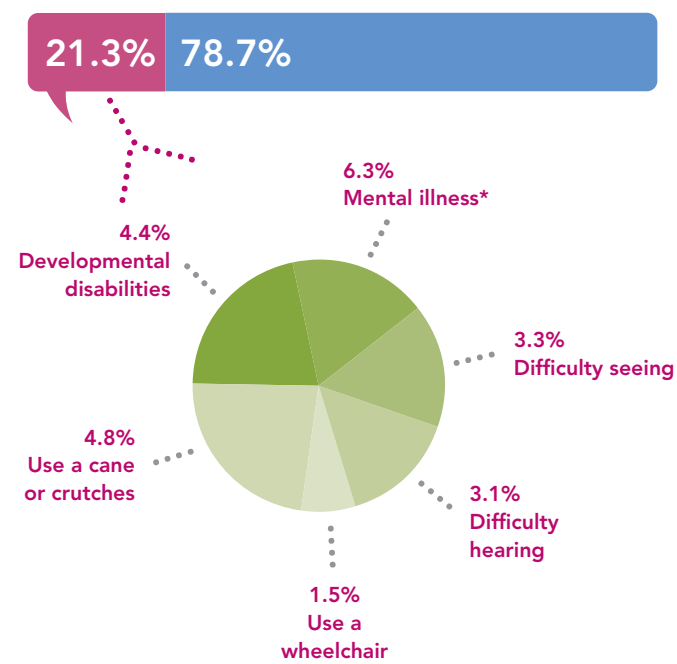
*About one in four adults suffers from a diagnosable mental disorder in a given year. [2]

NOTE: Inclusion Solutions also engaged a meeting with the Recovery and Addiction community which is not counted in U.S. Census information. "It has been estimated that nearly one in every 13 adults is an alcoholic.[3] Further, in 2012, an estimated 23.9 million Americans aged 12 or older were current (past month) illicit drug users, representing 9.2 percent of the population aged 12 or older. [4]

Sources:
[1] U.S. Census Bureau, "Americans With Disabilities: 2010" issued July 2012.
[2] "The Numbers Count: Mental Disorders in America," National Institute of Mental Health, 2012.
[3] http://www.projectknow.com/research/drug-addiction-statistics-alcoholism-statistics/#alcoholism-statistics-in-the-us
[4] Substance Abuse and Mental Health Services Administration, Results from the 2011 National Survey on Drug Use and Health: Summary of National Findings, NSDUH Series H-44, HHS Publication No. (SMA) 12-4713. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2012.

METHODOLOGY

"We created a two-way street instead of two one-way streets."

1. Identify a leader who will bring others to the meeting.
2. Enrollment.
3. Make it safe, real and fun.
4. Listen! And <u>show</u> you are listening!

1. Identify a leader who will bring others to the meeting.

Buff Hennessey is Executive Director of The Arc Southeastern Minnesota. When presenting to Mayor Ardell F. Brede on May 9, 2014, she proclaimed that she and Patrick "had the longest phone tag exchange in recorded history".

> This is not incidental. A leader who will bring others to the meeting is almost always busy, engaged with many projects, and therefore hard to reach.

When Patrick and Buff finally spoke, the conversation was personal. Both have an Irish heritage; both enjoyed talking about their trips to Ireland and sharing stories about their extended families.

> The world of disabilities is a personal world. Disabilities are often hidden, and often a source of dissonant emotion. A leader in this world is one who "makes visible the unspoken" — who has the courage to share what is personal and by doing so access what is hidden. Only then can the "authentic dialogue" required by FEMA occur.

Buff was named frequently by others in Patrick's telephone inquiries. "You have to talk to Buff Hennessey about that." "Have you spoken to Buff?"

> Leaders are social. They like people, connect to people, know people, and are named by people. They become the "draw" for the event, as people "first follow the person, then the plan" (James M. Kouzes, "The Leadership Challenge").

Buff Hennessey
Executive Director of The Arc
Southeastern Minnesota

2. Enrollment.

Knowing who to talk to is the first step; knowing how to enroll is the second.

Enrollment requires knowing the culture of the community. When speaking to Tracy Bell, Regional manager, Deaf and Hard of Hearing Services Division — Southern Region (Minnesota), Patrick asked "do you want to text or VP (videophone)?" It is by being familiar with the deaf community and the customization of communications that one gains the credibility needed to enroll, reinforcing the concept of meeting people where they are.

Credibility creates trust. Many people with disabilities find it difficult to trust those in the larger community… and feel isolated.

> In our meeting with the deaf community, it became clear that first responders (police) could be perceived as threatening — because events occur faster than the speed at which communication occurs, sometimes producing anger and the tendency to be dismissive on the part of the responder (and corresponding defensiveness and frustration on the part of the citizen).

3. Make it safe, real and fun.

"Heavy" meetings produce light results. It is only when people — especially people with disabilities — feel safe and believe that the conversation is authentic — that real communication takes place.

> Notice the look and feel of the sample invitation for the deaf community (Appendix I). It is colorful (fun), it is real (three logos on the top), it is safe (feel free to bring your children). It uses exclamation points to add to levity. It is simple to understand and direct.

To make it safe, real and fun (and access the maximum contribution) Inclusion Solutions deliberately did not act like consultants, like "experts". Rather, the approach was to be educated facilitators: people who knew the culture of the community and respected that culture, and who genuinely wanted to learn what we did not know about emergency planning.

> Every meeting began with a simple exercise: asking each participant where s/he was born and what was outside the window. By bringing back memories of childhood and an image connected to growing up, one brings safety into the room. One also learns the starting point of every conversation and contribution.

People on city bus touring Mental Health sites

4. Listen! And SHOW you are listening!

Listening is demonstrated in two ways:

- by asking questions;
- by showing one is listening by taking notes.

At every meeting, officials from the county and city visibly took notes — in front of each member of the community. Taking notes demonstrates listening, and does so without the "camera effect" of recording the meeting (which can attract people who want to be seen, but may or may not have something to contribute).

Amy Evans, Emergency Preparedness Coordinator, Olmsted County Public Health Services summarized the process best: "We created a two-way street instead of two one-way streets."

FINALLY: Assess Progress, "Buy-In"

FEMA's Local Mitigation Planning Handbook (March 2013) states the following:

> A key element in the mitigation planning process is the discussion it promotes among community members about creating a safer, more disaster-resilient community. A plan that accurately reflects the community's values and priorities is likely to have greater legitimacy and "buy-in" and greater success in implementing mitigation actions and projects to reduce risk. (p. 3–1)

FEMA calls this element of the planning process "Task 3: Create an Outreach Strategy". To measure our success in executing Task 3, Inclusion Solutions asked meeting participants to complete a Pre-Assessment and Post-Assessment questionnaire.

We measure the level of engagement — the level of "buy-in" — as the percentage change in participant attitudes between Pre- and Post-Assessment. The best measure is the TOTAL change. This measured change (delta) was greatest for the Deaf and Hard of Hearing Community (+68%) and lowest for the Senior Community (+5%). The average change for all groups was +25%.

Results of these assessments appear in the Scores chart for each community group visited and in Appendix V.

MEETING SUMMARIES

MENTAL ILLNESS / MENTAL HEALTH

Captain: Courtney Lawson, Executive Director, NAMI SE Minnesota

Location: Olmsted County Public Health Building, 2100 Campus Dr SE, Rochester

Agenda: See Appendix III

In Brief:

Jenna Benson and Carrie Clark spoke about their experience with mental illness and how it may be impacted by emergency management events. The group boarded a bus and traveled to locations in the community that provide services for those with mental illness. At each location, we heard a summary of the organization's purpose and information about who they serve.

Jenna describes her personal story

Take Aways:

- Mental illness is often invisible – and temporary.
- Some locations would be difficult to access by public transportation in cases of emergency.
- Those with mental illness seek stability and comfort: access to medications is important, as is the availability to talk to someone when needed.
- Security is important: those with mental illness feel more vulnerable (opposite of those in recovery and addiction, who see "opportunity").
- Observation from Ken Jones: Those with mental illness tend to see the world as filled with police (fear, enforcement, force); whereas those with developmental disabilities tend to see the world as filled with firemen (heroes, safety, immediate trust).

Scores:

	PRE	POST	DELTA
Relationship with Emergency Management	4.5	5.0	**+11%**
Emergency Management has People with Disabilities in mind	2.9	4.0	**+38%**
I can contribute	4.2	4.5	**+7%**
Personal Preparedness	3.2	4.7	**+47%**
TOTAL	**14.8**	**18.2**	**23%**

Jeff and Terry on the bus together

DEVELOPMENTAL DISABILITIES

Captain: Buff Hennessy, Executive Director, The Arc, Southeastern Minnesota

Location: 3008 Wellner Drive NE, Rochester, MN 55906

In Brief:

Buff Hennessey hosted our meeting at the corporate offices of Cardinal of Minnesota, LTD. We boarded a city bus and visited two (of 120) group homes and two private residences where people with developmental disabilities live.

The last stop on our tour was Hiawatha Homes Activity Center, Inc., where young people with developmental disabilities "drop in" during the day, cook meals, relax, do homework, etc.

Take Aways:

- The group homes we visited had thought through and posted their emergency plans.
- Group homes are integrated into larger neighborhoods (not clustered) — and the neighbors are part of the care and concern mix.
- Homes are not "institutional" — more like family
- People with developmental disabilities usually live with staff or family members (not completely independent).

Planners congregate outside of residence

Scores:

	PRE	POST	DELTA
Relationship with Emergency Management	4.7	4.9	**+4%**
Emergency Management has People with Disabilities in mind	3.6	4.0	**+11%**
I can contribute	4.1	4.4	**+7%**
Personal Preparedness	3.6	4.8	**+36%**
TOTAL	**16.0**	**18.1**	**+16%**

Meeting at Jan's dining room table

BLIND

....

Captain: Jan Bailey, Treasurer, Past President, Rochester Chapter, National Federation of the Blind

Location: Home of Jan Bailey

In Brief:

This was the location where Inclusion Solutions was most able to replicate the model that "all important conversations take place around the kitchen table." Food was served (a local favorite: Canadian Honker) for 12. The group split into two to address questions regarding how the blind community responds to emergencies.

Take Aways:

- The blind community has a strong relationship with the Lion's Club – provided rides to the meeting.
- I learned that news is becoming more franchised and less local – making communication regarding impending weather events, etc., less available.
- How direction is expressed matters! "Here to there" is useless; "north to south" is meaningful.
- Transportation is a big issue for the blind community (no one can get from here to there without assistance). "Evacuations are a concern especially within the limitations of Rochester's bus system." (participant).
- "Rely on own networks before government agencies." When asked by Jeff Ellerbusch, one participant commented that neighborhood groups and neighbors matter.

Captain Jan Bailey

- "Another critical piece of equipment is the baseball cap. The bill on the cap provides three inches of protection from things you may run into." A perfect example of the nuances one learns in such meetings.
- Low percentage of blind people read Braille (from 2–10%).
- Websites matter more…accessibility important.
- "Phone calls best for immediate danger; texts and emails for impending events."

Scores:

	PRE	POST	DELTA
Relationship with Emergency Management	4.7	4.8	**+2%**
Emergency Management has People with Disabilities in mind	2.7	3.4	**+26%**
I can contribute	3.4	4.2	**+24%**
Personal Preparedness	3.1	4.8	**+55%**
TOTAL	**13.9**	**17.2**	**+31%**

DEAF AND HARD OF HEARING

Captain: Tracy Bell, Regional Manager, Minnesota Department of Human Services / Deaf and Hard of Hearing Services

Location: IBEW Local 343, 9 80th Street SE, Rochester, MN 55904

In Brief:

In our best attended meeting, we hosted nearly thirty 30 deaf citizens to pizza. Six interpreters were present for this large group to meet everyone's communication needs, including those who could hear — as those who are hearing wouldn't be able to get information from the deaf community without interpreters.

Interpretive services made available included CART (Communication Access Realtime Translation), a deaf interpreter who "copied sign" for a deafblind individual, and ASL interpreters.

The presence of these interpretive services made a significant impact on the perception of the community.

Take Aways:

- "Hunger" to be heard was evidenced in the largest increase in overall scores.
- Texting is an oft-used method of communication between people who are deaf – however, one cannot assume everyone has access to a smart phone.
- Unlike other disability communities, the deaf often require an intermediary: an interpreter.
- There was much concern voiced about what occurs when there are accidents involving injury and police: fear of poor communication or misunderstandings. Great concern that "writing it down" is insufficient in traumatic situation involving injury and requiring fast response.
- Desire to have more interpreters available in Rochester — any measurements available on demand? We understood Mayo Clinic has two interpreters on staff.
- Responders should be aware that many notification systems do not work for the deaf community (sirens, automated phone calls not integrated with videophone equipment, etc.).

Ken introducing Emergency Management to the deaf community while Jimmy interprets in sign language

Scores:

	PRE	POST	DELTA
Relationship with Emergency Management	4.4	4.9	**+11%**
Emergency Management has People with Disabilities in mind	3.0	3.8	**+27%**
I can contribute	4.0	4.3	**+8%**
Personal Preparedness	3.0	4.5	**+50%**
TOTAL	**10.4**	**17.5**	**+68%**

Patty interprets the meeting while Lloyd looks on

Group meeting for people with physical disabilities

PHYSICAL DISABILITIES

Captain: Robert Weigel, Independent Living Coordinator/Accessibility Specialist, Southeastern Minnesota Center for Independent Living (SEMCIL)

Location: 2200 2nd Street SW, Rochester, MN 55902

In Brief:

- Building access, electronics, generators
- Before / after
- Transportation
- Power outages
- Access to medications

Adam

Take Aways:

- Smart phones are used as primary communication tool.
- Many live in a world of "before" (injury) and "after" (injury).
- Backup systems and caretakers are a common part of daily life.
- Once in bed, one may only have access to phones; Personal Care Assistants (PCAs) may not be available.
- Most buses can handle no more than two people using wheelchairs.
- It takes longer to move from point A to point B; time and early warning are important.
- "A minor emergency for most people is a big emergency for me."
- Medications should be taken into account when evacuating.
- Registries are controversial: concern about vulnerability and concern about being left behind.

Scores:

	PRE	POST	DELTA
Relationship with Emergency Management	4.5	4.9	**+9%**
Emergency Management has People with Disabilities in mind	3.1	4.2	**+29%**
I can contribute	3.4	4.2	**+25%**
Personal Preparedness	2.6	4.7	**+81%**
TOTAL	**13.6**	**18.0**	**+32%**

Local seniors in a group discussion

SENIORS

Captain: Julie Gran, Program Director, Rochester Senior Center

Location: 121 N. Broadway, Rochester, MN 55906

In Brief:

The meeting was attended by several clients of the Rochester Senior Center and staff members of the Red Cross, Salvation Army, and Family Service Rochester. The question of whether older adults should be "lumped in" with those with disabilities was discussed.

Take Aways:

- Affirmation that older adults prefer to rely on the technology they grew up with (e.g., siren, TV alerts, etc.).
- Social media is growing due to connection with grandchildren.
- Potential for isolation in community is greater than for other groups.
- More comfortable using "traditional" means to express views (call City Council, call Donna at the Mayor's office).
- Difficult to inspire and move (see Scores).

Scores:

	PRE	POST	DELTA
Relationship with Emergency Management	4.4	4.4	**+0%**
Emergency Management has People with Disabilities in mind	3.4	3.4	**+0%**
I can contribute	3.5	3.9	**+11%**
Personal Preparedness	4.0	4.4	**+10%**
TOTAL	**15.3**	**16.1**	**+5%**

Kevin listening to Lad

RECOVERY COMMUNITY

Captain: Trent Fluegel, Executive Director,
   Interfaith Hospitality Network

Location: Rochester Public Library

In Brief:

- Anonymity
- Resiliency
- Possible untapped resource

Take Aways:

- Disaster = Opportunity: chaos creates opportunity to obtain drugs and narcotics.
- Impending Threat = Stimulant: charges up drug abusers.
- Privacy issues created by "communicating with the anonymous": those who want to keep drug abuse private tend not to want to be on lists.
- Methadone clinics have a one week supply.
- Eighty-two AA meetings every week in Rochester.
- Twelve Step groups may be a volunteer resource.
- Tremendous resiliency in this population: they are "survivors".
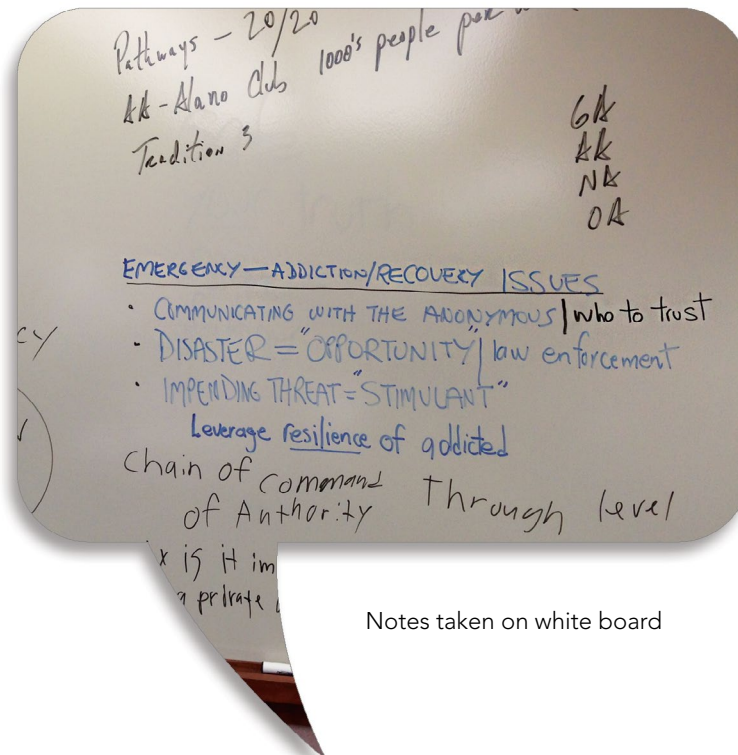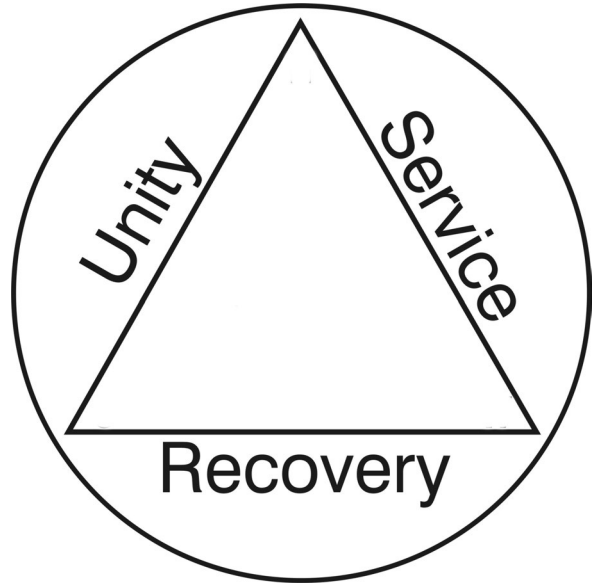
Notes taken on white board

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Rochester street sign

Amy and Lad enjoying a moment

RECOMMENDATIONS

In a meeting with Mayor Ardell F. Brede on May 9, 2014, Inclusion Solutions presented its findings and recommendations by asking key participants in the week to speak. Remembering that "the plan is only as good as the process and people involved in its development" this provided an ideal opportunity for the process and people with whom relationships were developed to be heard. The key recommendations (as outlined in the High Level Summary of Findings) were:

- Access contribution from community members with access and functional needs by engaging and meeting them where they live their lives. We say it this way: **in order to be deserving of contribution from you, I must go to you**.
- Continue all dialogues and information gathering by respecting the differences among people with disabilities. It is not true that a person affected by addiction and recovery will have the same needs, communication styles, and interests as one who is blind or physically disabled. This is best accomplished by speaking to people within groups separately.
- Ask for contribution! People want to contribute — and will do so if the setting is safe, real and fun.
- Remember that authentic dialogue as required by FEMA occurs "at the kitchen table". Always have this vision in mind as you continue conversation with members of the community.
- Finally, continue conversation with members of the community. Continuing relationships with those in the community with access and functional needs requires continuous conversation.

Inclusion Solutions also left a video of an interview with Karen M. Tamley, Commissioner, Mayor's Office for People with Disabilities (MOPD) in Chicago. We recommend that the City of Rochester consider creating such a position to ensure that disability is part of every conversation the city has as it develops its All Hazard Mitigation Plan, City Streets Plan.