

SUMMARY REPORT 2006

**“INCLUSIVE COMMUNITIES – AGING AND
DEVELOPMENTAL DISABILITIES: PLANNING AND
BEST PRACTICES”**

**Aging & Developmental
Disabilities**

WORKSHOP

**NORTH WEST
REGION**

Thursday March 30, 2006

Friday, March 31, 2006

Travelodge, Airline Hotel, Thunder Bay, ON

TABLE OF CONTENTS

1.0	Executive Summary		3
2.0	Workshop Agendas		5
3.0	Highlights of Information/Training Sessions		7
4.0	Group Discussions		9
5.0	Workshop Planning Committee		19
6.0	Evaluation Report		20
7.0	Appendix A: Thursday Handout Material		42
8.0	Appendix B: Friday Handout Material		54

1.0 EXECUTIVE SUMMARY

A two-day workshop on Aging and Developmental Disabilities was held in Thunder Bay, Ontario on Thursday March 30 and Friday March 31, 2006.

The evening of Thursday March 30 involved a presentation entitled *Aging and Developmental Disabilities – Healthy Perspectives* given by Leslie Udell of Winnserv Inc., Winnipeg, Manitoba. A total of 47 people attended. The participants included management, direct support staff and self-advocates from both the city of Thunder Bay (24) and the region of Thunder Bay (23).

On Friday March 31, 76 attended a full day session entitled *Inclusive Communities – Aging and Developmental Disabilities: Planning and Best Practices*. The participants included management, direct support workers, family, and self-advocates, from both the city of Thunder Bay (52) and the region of Thunder Bay (24).

The Friday morning session consisted of an educational component with guest speakers – Dr. Roy Brown, Leslie Udell, Bernie Travis, Laura Kokocinski, and Ron Coristine. In the afternoon, facilitated discussions were held to look at success stories/best practices, issues/barriers, strategies/solutions and priority areas to address sustaining community living for individuals aging with a developmental disability in Thunder Bay and the region.

Small group discussions identified various success stories/best practices providing a sense of optimism. Numerous barriers/issues were identified, including:

- Increased/unique individual needs
- Informal and formal supports
- Current attitudes
- Infrastructure
- Education
- Limited individual and systemic resources
- Policy/procedures

A range of strategies/solutions were identified as possible means to overcome some of the issues/barriers, including:

- Partnerships/collaboration between service sectors
- Creativity/choice in services
- Planning
- Education/training opportunities
- Data collection/research

Priority areas identified by the small groups were:

- Establishment of partnerships/collaboration between all partners in care, such as families, self-advocates, non-profit, health, municipality, MCSS, agencies, in relation to accommodation alternatives and planning for life transitions
- Creative solutions within existing resources in relation to accommodation alternatives and sustaining and supporting the caregiver
- Developing policies/protocols regarding end of life care

- Advanced planning in relation to end of life care and planning for life transitions
- Education and awareness for various parties, such as individuals supported, advocates, staff, public/community regarding all aspects of aging with a developmental disability, life enrichment through activity, planning for life transitions, and enhancing health promotion
- Advocating for both individual and systemic financial resources for life enriching activities and to aid in planning for life transitions
- Accessibility and availability of life enriching activities
- Improving communication to enhance health and to give people a voice regarding sustaining and supporting the caregiver

For further detail please see the 'Group Discussions' section of this report.

At the end of the day nine individuals expressed an interest to be involved in the future initiatives of the Aging and Developmental Disabilities Committee of Northwestern Ontario (ADDCNWO). The ADDCNWO now begins the task of determining strategies to address the priorities established by workshop participants.

I congratulate all of the participants for contributing to this body of work that will provide a solid foundation for future efforts to better service and support individuals who are aging with a developmental disability. It was a day well spent.

Sincerely,

Charlene Lopenen

2.0 WORKSHOP AGENDAS



Aging and Developmental Disabilities: Healthy Perspectives

Thursday, March 30, 2006
Travelodge, Airline Hotel, Thunder Bay, ON

AGENDA

6:30pm – 7:00pm	Registration / Agency Displays	
7:00pm – 7:05pm	Welcome Introduction of Keynote Speaker	Karen Maddox Terry Lowey
7:05pm – 8:05pm	Keynote Presentation 'Aging and Developmental Disabilities: Healthy Perspectives'	Leslie Udell
8:05pm – 8:25pm	Question Period	Leslie Udell
8:25pm – 8:30pm	Wrap Up/Closing Remarks & Evaluation	Karen Maddox Terry Lowey

WORKSHOPNORTH WEST
REGION**Inclusive Communities – Aging and Developmental Disabilities:
Planning and Best Practices****Friday, March 31st, 2006**

Travelodge, Airlane Hotel, Thunder Bay, ON

WORKSHOP AGENDA

8:00 – 8:30	Registration / Agency Displays
8:30 – 8:50	Welcome and Progress Made Since 2001 Workshop Karen Maddox/Terry Lowey
8:50 – 9:00	Ontario Partnership on Aging and Developmental Disabilities (OPADD) Ron Coristine
9:00 – 10:00	Keynote Presentation 'Challenges and Opportunities in a Changing World' Dr. Roy Brown
10:00 – 10:15	Question Period Dr. Roy Brown
10:15 – 10:30	Break / Agency Displays
10:30 – 11:00	North West Local Health Integration Network Presentation 'Building a True System: Are You Ready?' Laura Kokocinski
11:00 – 11:45	Panel Discussion 'Fostering Change at the Local Level' Dr. Roy Brown; Leslie Udell; Bernie Travis
11:45 – 12:15	Video 'The Art of Possibilities' Sandra Dewsberry
12:15 – 1:00	Lunch / Agency Displays
1:00 – 1:30	Introduction to Small Group Discussions Leslie Udell
1:30 – 2:30	Small Group Discussions Facilitators
2:30 – 2:45	Break / Agency Displays
2:45 – 3:45	Facilitated Large Group Discussion Leslie Udell
3:45 – 4:00	Wrap Up / Closing Remarks / Evaluation Karen Maddox/Terry Lowey

2.0 HIGHLIGHTS OF INFORMATION/TRAINING SESSIONS

THURSDAY MARCH 30, 2006

Keynote Presentation

“Aging and Developmental Disabilities: Healthy Perspectives” Leslie Udell

Leslie Udell spoke to: Elements of a healthy lifestyle; Growing older with an intellectual disability; Growing older with other co-morbid conditions; Social and emotional contributions to health; and Barriers to good health care. A question period followed.

Agency Displays

The following agencies had their programs/services on display:

- Community Care Access Centre
- Shoppers Home Health Care
- Lutheran Community Care Centre
- Wesway
- Community Living Thunder Bay
- Ontario Partnership on Aging and Developmental Disabilities
- Inclusion Services
- Centre for Education and Research on Aging and Health

*Please see Appendix A for a copy of the Thursday handout material.

FRIDAY MARCH 31, 2006

Keynote Presentation

“Ageing and Developmental Disabilities - Challenges and Opportunities in a Changing World” Dr. Roy I. Brown

People with developmental disabilities are living much longer and many challenges are emerging for individuals, their families, and personnel. Policies and practices need to be redefined to take account of these changes. Needs are often complex. Individuals, now elderly, who were once institutionalized, require support and care. Others, who have lived their lives at home and in the community, require varied support as individuals move into the upper age brackets. Both preparation for ageing and services for the older individual are necessary. The resources required are holistic and yet needs are individual and various.

This presentation looks at some of these challenges through the lens of quality of life. This approach, developed within the field of developmental disabilities, has provided a way of viewing disability in a new light, and helped us to look at some of the challenges in an holistic and a lifespan fashion while taking into account previous work such as inclusion and discrimination. The quality of life approach will be introduced and discussed in practical terms recognizing both individual and community issues. Examples will be provided in terms of families, services and policies. We will look at issues of inclusion and discrimination and discuss how the practice of frontline practitioners and

service managers are likely to be challenged in terms of ethical and professional practice. Through a series of examples and vignettes the issues will be presented to raise important aspects of practical application and research to encourage dynamic problem solving amongst the audience.

North West Local Integration Health Network (NW LHIN) Presentation

“Building a True System: Are You Ready?” Laura Kokocinski

Panel Discussion

“Fostering Change at the Local Level” Dr. Roy I. Brown; Leslie Udell; Bernie Travis

- Each panelist spoke for five minutes to the following question: From your perspective how do you foster change at a local level? The floor was then open for questions.

Video

“The Art of Possibilities”

- This video about leadership was shown during lunch.

Small and Large Group Discussions

- These discussions took place in the afternoon and are discussed in the next section of this report

Agency Displays

The following agencies had their programs/services on display:

- Community Care Access Centre
- Shoppers Home Health Care
- Lutheran Community Care Centre
- Wesway
- Community Living Thunder Bay
- Ontario Partnership on Aging and Developmental Disabilities
- Inclusion Services
- Centre for Education and Research on Aging and Health

*Please see Appendix B for a copy of the Friday handout material.

4.0 GROUP DISCUSSIONS

SMALL GROUP DISCUSSIONS

Participants at the Aging and Developmental Disabilities Workshop held on March 31, 2006 in Thunder Bay, were organized into ten small discussion groups to discuss and record success stories/best practices, issues/barriers, strategies/solutions, and priority areas to address in order to sustain community living for individuals aging with a developmental disability in Thunder Bay and the region. Each small group discussion was based on a particular theme. The ten groups, according to theme, were: Planning for Life Transitions (2 groups), Accommodation Alternatives (2 groups), End-of-Life Care (2 groups), Life Enrichment Through Activity (2 groups), Enhancing Health Promotion (1 group), and Supporting and Sustaining the Caregiver (1 group). All participants were placed into their first or second choice of themed small group discussion. The groups were preplanned to include representation from both sectors as well as representation from Thunder Bay and the region.

Within the discussion groups, a facilitator ensured that the group addressed the following four questions:

- What are some examples of success stories or best practices regarding your theme?
- What are the issues or barriers to providing support in relation to this theme?
- What are some potential strategies or solutions to overcome these issues or barriers?
- What do you consider are the 2 priorities to address in relation to this theme in order to sustain community living for adults aging with a developmental disability in Thunder Bay and the region?

The discussion was recorded on flip charts and presented to the larger group.

This report of the afternoon's proceedings is provided as a record of the event. The discussions recorded here are verbatim. The record of one small group discussion, 'End-of-Life Care – Group C1,' was not received and therefore not included in this report.

Planning for Life Transitions

Success stories/Best practices

- Transition to long-term care
 - 6 months of support to staff and client
- Transition of mother and daughter to long-term care together
- Successful transition from waitlist – services – job – to community inclusion with the help of multi-disciplinary team
- Self advocate educating others with video on inclusion
 - From institution to community- employee – active retired volunteer
- Data Collection

- Baseline at age 40 BP
- Project Housing Needs
 - Networked with an independent landlord to develop appropriate housing
- Planning – monthly, yearly; one person at a time with self-advocates, staff, family: holistic
- Planning Ahead rather than crisis management
 - PCP's look to the future
 - developing support circles for people
- Connect with community programs
- Family home providers
- Filling empty beds in a timely manner

Issues/Barriers

- Increased needs due to aging (at earlier age)
- Needs different from others in one's home
- Need for changes in physical adaptations (personal/environmental)
- Ailing health
- Funding
- Reduction/failure to increase funding/benefits (ODSP, homemaker program, MCSS)
- Gap in services provided by Ministry of Health and MCSS funded programs
- Filling empty beds in a timely manner
- Waiting lists
- Problem with first transition from home to community (waiting lists)
- Established relationships in developmental services
- Breakdown in family support (parents passing away)
- Providing appropriate matches
- Lack of awareness, knowledge, skills
- Parents reluctance to plan ahead
- Knowledge of clients in the community who will be in Transition in the future
- Fear (parents, consumers, staff)
- Guilt of Caregivers
- Staff attitude (change/work)

Strategies/Solutions

- Education to clients in the community who will be in transition in the future
- Education to address the fear of parents, consumers, staff
- Training to address the lack of awareness, knowledge, skills
- Training to address the issue of staff attitudes
- Inspiring
- Break away
- Outside facilitators
- Information to individuals to aid in decision making
- Networking/collaboration
- Networking with community/health resources (BC model)
- Dialogue between MCSS at Ministry of Health consumers

- Data collection; Demonstrate the need; Credible data
- Identify clients in the community who will be in transition in the future
- Review wait list needs
- Agencies need to plan ahead
- Plan before crisis. Natural support important.
- Open communication
- Video conferencing (Dryden)
- Build in ways of keeping friendships alive
- Develop trusting relationships
- Creative offer of service
- Choice/Empowerment
- Active outreach to clients in the community who will be in transition in the future through faith communities, nursing stations
- Agency policies to address the lack of awareness, knowledge, skills

Priorities

- Funding
 - Staff retention
 - Additional staff
 - Wait lists
- Education – removing barriers (with self advocates)
- Commitment from all sectors, using a method of collaboration to focus on the goals of the individual going through the transition
- Planning
 - Gathering information
 - Data collection
 - Demonstrate the need

Accommodation Alternatives

Success stories/Best practices

- Adult children rent family home
- Family home program
- Adapting environments e.g. core floor
- Supports for ‘aging in place’ (in natural family home)
 - Respite, CCAC
- Inter-sectoral planning for people to develop best solutions in meeting needs-sharing resources e.g. home dialysis – Atikokan by ACL
- Specialized training for front line staff

Issues/Barriers

- Lack of affordable housing
- Lack of accessible housing

- Lack of suitable (non-slum) housing
- Lack of supportive housing
- Money!!!
- ODSP – D.A.S. (<\$)
- Tunnel vision (unwilling to change) outmoded societal attitudes
- Lack of understanding of each other's sectors
- Inter-org. attitudes affecting how services are delivered (funding issues, capacity issues)
- Lack of a healthy lifestyle; lack of inclusive expectations
- Social issues: drugs alcoholism
- Lack of creativity in exploring alternatives (fear of doing business differently – taking a risk)
- Dignity of risk (fear of)
- Ownership/mandate (whose job is it?; person-centered)

Strategies/Solutions

- Don't just talk about solutions/changes – do it!
- Cross-board fertilization
- Changing attitudes – at all levels: via education/example, pilot projects
- Learning from + changes in education system, parent groups
- Good planning – (person-centred)
- Support circles

Priorities

- Partnerships, in relation to accommodation (families, self-advocates, non-profit, health, municipality, MCSS, agencies)
- Empowering creative solutions at front line level, 1 person at a time

End-of-Life Care

Success stories/Best practices

- Caring staff
- Involvement of family
- Support system in place
- Maintain connections
- Access other assistance
- Compassion – teams pull together
- Organizations developed committees and subcommittees on ELC
- Dedication of all areas
- Sharing experiences and memories
- Open communication
- Celebration of life

Issues/Barriers

- Lack of family involvement
- Communication, and comfort of passing along the changes in the individual to their friends/housemates
- Trying to keep stability and still deal with situation – different support issues
- Personal feelings/values
 - Too invested in person
 - Grief vs. responsibilities
- Conflict regarding wishes vs. family ideas
- Unclear to family of who is responsible for decision making
- Lack of end of life policy/procedures
- Lack of medical knowledge/end of life
- Uncertainty of process
- Advance care planning
- Lack of planning
- Medical and physical needs of ill/dying individual
- Lack of human resources for quality care

Strategies/Solutions

- Develop advance care planning for each individual under support
- Planning ahead
- Pre-planning for individuals prior to decline (right place at right time)
 - Residentially
- Develop committee on EOLC
- Agency needs an end-of life care person?
 - Portfolio
 - Team
- Develop policies/protocols surrounding end of life care
 - Levels/involvement of care
 - After end of life process
- Educate and counseling/mentoring of support staff
 - Within agency; admin and front line; family
 - Strong linkages with outside agencies

Priorities

- Develop policies/protocols surrounding end of life care
 - Levels/involvement of care
 - After end of life process
- Develop advance care planning for each individual under support. Pre-planning for individuals prior to decline (right place at right time)
 - Residentially

Life Enrichment Through Activity

Success stories/Best practices

- Inclusion Services: June 2005: Partnership between the city of Thunder Bay and many Thunder Bay community resources using services available
 - Peer support; facilitation
 - 1:1 and 2:1 friends
 - Female 55+ now more independent and not fearful
 - Rec history, advocate, communicate with others
 - Work with supports available
 - Helps to include in group already running
- Promoting inclusion through partnership with the city (recreation services, seniors centers)
- Support Special Olympics events/activities
- Special Olympics
 - Everyone gets recognition
 - Going from not participating to ++ participation – other social aspects such as dances
 - P.R.
- 1 yr funding to develop a volunteer pool
 - Best buddy system – peer mentor
 - Best buddies
- Best Buddies – College, University, high school/CFF
 - Choices – look at skills, match with others
- Pal Card – city facilitates and some private facilities – allows person with DD to have a support person with them (no fee for support person)
- Support staff for people participating in activities no longer have to pay as PAL card pays one fare
- Therapeutic gardening program
- ‘Mandatory’ wellness activity (exercise etc.) 1 hr/day Mon-Fri at day services and also 1 hr/day on weekends at group homes
- Pet therapy in the group home
- Vacation/Leisure Opportunities
- Participation in organized community activities. Concerts, sporting events, etc.
- Church activities/groups...bingo and picnics
- Person centred planning
- Coordinating services/family members
- Volunteers
 - Art display, cooking classes
 - Variety of ages
 - Some have d.d

Issues/Barriers

- Financial – individuals, system
- “\$”

- Support needs vs. support money
 - For activity not just ‘care’ (discomfort/fear of staff)
- Conditional ‘freebies’
- Transportation – city and to other communities
- Infrastructure, e.g. state of the community – sidewalks, roads, snow removal
- Accessibility of buildings etc. in communities
- Transportation – accessibility, cost
- Age – generational perceptions
- Attitude
- People’s perception-some community members are still learning about inclusion
- Physical – aging (adapting)
- Person themselves
- Health status of the people we support
- Youth-What happens between child and adult? Where are the youth?
- Family – protection
- Support staff – whose likes/dislikes values are we looking at? Whose in control?
- Community involvement
- Community capacity – availability of activities in smaller communities
- Education – DD and/or aging
 - How to treat/interact with people who have DD
- Not enough education at younger age
- Behaviours – whose responsibility
- Liability and risk

Strategies/Solutions

- Education – staff, physicians, family
- Wellness presentations
- Education – attitude of H.C.P.
- Education for support staff to advocate/facilitate
- Word of mouth-1:1 education
- Promoting community awareness and education
- Choice, involvement in the activity process (person/people with DD)
- Need to provide opportunities for choices, to vocalize wishes (may need to do so several times)
- How often do we make ‘bad’ choices?
- Giving freedom to people and their support teams to find solutions to overcoming barriers to participating in activities
- Giving the choice to the people re: freebies – do people want to accept the conditions (e.g. seat selection) –ask the donor to remove the conditions
- Staff discomfort/fear – Rule #6
- Municipalities, as part of their planning, must include the needs of the members of our society who have a disability
- Advocate for more money for people to use for transportation for community involvement (fee, ODSP)
- Commitment from agency – commitment to mission, values
- Buy in from admin/supervisor, (vocal) –advocates as well
- Inclusion into mainstream

- Working with professionals to adapt activities to include everyone regardless of health status
- Dealing with infrastructure – involvement with community accessibility committees and municipalities; supporting people to advocate for community/municipality changes
- Community transportation – can funding be accessed, fundraising to subsidize the costs – more flexibility?
- Get to know person-trusting relationship
- Not what can't they do it; what can they do it?
- Active participant
- At what level are you active in an activity? Adapt the level of participation. A person may want to watch or socialize
- Physical – medical interventions (thyroid, UTI) – asking ??'s
- PAL card – helps reduce economic stress
- Liability – proper insurance – liability should be evaluated on an individual basis to identify risk

Priorities

- Education and awareness
 - For seniors with disabilities – empowerment
 - For advocates
 - All aspects
- Financial - systematic, individual
- Accessibility to activity
- Availability of a variety of activities

Enhancing Health Promotion

Success stories/Best practices

- Introducing new opportunities – Fitness, Cat Cuddle
- Developing new relationships trust
- Choice of activity
- Brings community into the home
- Integrated programming
- Bring organizations together – support, info, resources, end of life care at home
- Developing more independence
- Discuss healthy lifestyle choices

Issues/Barriers

- Dignity of risk – not happening
- Consistency of direction
- Ownership
- Knowledge/resources at home, low/no cost fitness

- Staff/care providers/families education
 - Knowledge of healthy food choices/affordable
- Dental issues/knowledge of alternatives
- Communication between care providers/family/volunteers
- Attitude – staff, community

Strategies/Solutions

- Education – role model
- Community knowledge
- Communication – families, staff, volunteers, respite workers

Priorities

- Consistent approach from everyone in a persons life through communication – start with the person, discover goals reach them together
- Education – public/community, individual’s, staff

Supporting and Sustaining the Caregiver

(Caregiver-family, staff, volunteers, other service providers)

Success stories/Best practices

- Respite care services – a flexible range of options
- An open work environment that invites the self-expression of front-line staff (e.g. need for information/training/input on decisions) – e.g. palliative care, EAP
- Accreditation process gives affirmation to care providers
- Shared responsibilities among family members – augmented by service provider
- Cited instances of collaboration between MOHLTC and MCSS funded agencies – a result of dialogue/communication and identifying needs and who best to meet
- Everyone valued as part of team – removal of hierarchical barriers – looking beyond ‘old rules’ to respond to needs

Issues/Barriers

- Timeliness of support – things don’t happen quickly enough
- Roles sometimes too restrictive – creates gaps and ‘turf protection’
- Liability/risk often drives decision-making process
- Waiting lists
- Lack of funds/resources
- Inability to shift funds
- Policy – government and agency
- Lack of supportive H.R. policies within some organizations
- Communication challenges among various service providers
- ‘Not belonging’ – discrimination – come unrealistic – expectations, lack of understanding

Strategies/Solutions

- ‘Cross pollination’ in training/education cross-sectorally
- Nurture relationships/partnerships
- More opportunities to collaborate and co-operate – move beyond the ‘tables’ to action
- Build on the success stories
- Build incentives for creativity, innovation, risk-taking – a safe environment to brainstorm diverse solutions

Priorities

- Creative solutions within existing resources – including broader community and sharing
- Communication – give people a voice not tokenism

LARGE GROUP DISCUSSION

The large group discussion provided an opportunity for a participant from each small group discussion to present their group’s main discussion points to the larger group. Afterwards, Leslie Udell summarized the main success stories/best practices, issues/barriers, strategies/solutions, and priority areas.

5.0 WORKSHOP PLANNING COMMITTEE

Committee Members	Contact Information
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6.0 EVALUATION REPORT

THURSDAY MARCH 30, 2006

“Aging and Developmental Disabilities: Healthy Perspectives”

Of all 47 participants attending the Thursday evening presentation, 78.72% (37) filled out an evaluation form. The responses to the five evaluation questions were reviewed and categorized under main themes for the report. Admittedly, some interpretation was required. I apologize, in advance, for any attribution that may be perceived as erroneous.

Question One: Overall, how would you rate the presentation?

Overall, 54.06% (20) of respondents rated the presentation as excellent and 40.54% (15) rated it as very good. Only 2.70% (1) rated the presentation as good and 2.70% (1) rated it as fair. No one rated the presentation as poor.

Of the 37 respondents, 43.24% (16) made comments. These comments can be summarized as follows:

Leslie’s presentation skills (9)

- Excellent! Well presented!
- Excellent speaker, extremely knowledgeable with real examples and info
- Information was well presented
- Good overall presentation on topics discussed
- Valuable info presented clearly
- Lots of info presented – very respectful – an overview
- Very clear, easy to understand info, very clear speech
- Entertaining as well
- Enjoyed the presentation

Comments regarding general information presented (9)

- Very informative. Learned a lot
- Very informative
- Packed full of such good good info
- Lots of info presented – very respectful – an overview
- Good overall information on different causes for intellectual disabled problems
- Good relevant information
- Valuable info presented clearly
- Very knowledgeable presenter
- Excellent speaker, extremely knowledgeable with real examples and info

Comments regarding specific information presented (3)

- Very informative on health issues
- Good information about DS and the health
- Good information on DS, women and health issues

Question Two: What did you find most valuable about this evening's presentation?

Of the 37 respondents, 86.49% (32) answered this question. These comments can be summarized as follows:

Comments regarding general information presented (13)

- Informative
- Info was very informative
- Overall info
- Very good knowledgeable practical information, multifaceted
- Information useful in both work and personal settings
- Growing older with an intellectual disability section
- Good info and advice
- Content and clarity
- The topic and information
- Information resources to pass on to other service providers – general info – studies
- Reinforced knowledge
- Opening the dialogue
- Triggered plans for action

Comments regarding specific information presented

Different types of disabilities (5)

- Specific info on types of disabilities and ageing
- Information on aging for people with Down syndrome
- Medication and adverse effects. Down syndrome information
- Learning about Cerebral Palsy how it can get worse in many different ways. I myself find that if I don't exercise my mobility is worse. I have had Cerebral Palsy now for 37 years.
- Lots of valuable information on nutrition, thyroid diseases and health providers

Healthy lifestyles (4)

- Very informative on nutrition, exercise, and importance of healthy life style
- The importance of starting exercise when consumers are younger so that it becomes more positive
- How to approach client about exercise, nutrition
- Lots of valuable information on nutrition, thyroid diseases and health providers

Medications (3)

- Medication and adverse effects. Down syndrome information
- Information regarding Dilantin and website
- Information on Dilantin

Health (3)

- The information on health issues
- Health information
- Lots of valuable information on nutrition, thyroid diseases and health providers

Preventive health measures (2)

- I found the information regarding tests that everyone should have but don't get unbelievable-it is something to really start paying attention to
- Learning about the assessment starting to be offered to diagnose Alz's Disease-starting early with agencies – for medical profession. To take information on suspected Alz's early-chart changes-have same dr. talk it over with dr as they start changes.

Additional resources provided (4)

- The facts, stats and info places to go for resources
- Web site resource
- Information resources to pass on to other service providers – general info - studies
- Handouts – space to write own notes

Practical nature of information (3)

- Very good knowledgeable practical information, multifaceted
- Focused on what is really happening daily in our support of individuals
- Leslie's experiences and examples were very helpful

Leslie's presentation skills (3)

- Content and clarity
- Well organized
- Question period

Question Three: What did you find least valuable about this evening’s presentation?

Of the 37 respondents, 48.65% (18) answered this question. Of these 18 respondents, 55.56% (10) indicated that nothing was ‘least valuable’ in this presentation. Some of these respondents made additional comments. All comments can be summarized as follows:

Positive comments regarding the presentation (7)

- Everything applicable to our work and interesting
- Everything was valuable information
- All the information was important
- Good presentation
- Enjoyed all
- I do not support anyone with cerebral palsy; but the information was interesting/informative
- Lots of common sense information – helpful to have resources when dealing with medical profession

Lack of time to develop each idea fully (4)

- Maybe too many areas identified with little time to develop each one fully
- Time restriction allowed for ‘just touching’ on topics
- Not enough time to cover info
- Too short!

Particular topic areas (2)

- I do not support anyone with cerebral palsy; but the information was interesting/informative
- Learning about the assessment starting to be offered to diagnose Alz’s Disease-starting early with agencies – for medical profession. To take information on suspected Alz’s early-chart changes-have same dr. talk it over with dr as they start changes.

Not enough focus on regional perspectives (1)

- What happens in the ‘city,’ from a smaller center it is hard to get medical care on the most general care

Question Four: What education topics would you like to see offered in the future?

Of the 37 respondents, 56.76% (21) answered this question. All comments can be summarized as follows:

Specific types of disabilities (8)

- In depth training on specifics on types of disabilities
- How to teach our client to self exam/give us more details about their disease
- More info on Cerebral Palsy
- More on males with Down syndrome
- Individual and dementia & Alzheimer's & DS
- Aging in people with autism; more information on aging people with Down syndrome and Alzheimer/dementia
- More information on Alzheimer's and dementia in people with an intellectual disability and support strategies
- More on Alzheimer's/Dementia-in aging population-folks with intellectual disabilities

Forming partnerships/collaboration (5)

- How to work with Dr's etc on health issues with people with intellectual disabilities in a small community
- Working with health providers especially in small communities. Education is the key.
- More definite plan of action on how front-line staff can approach doctors with info or to improve their attitude and how to creatively involve our clientele to consider dr. examination, or getting more active
- Supporting individuals to get a diagnosis
- How can the educational system be involved in this process of understanding aging?

Preventive health measures (4)

- How to do an excellent assessment of individuals with dementia-what specific information should be looked at-what information is overlooked? What to do, what not to do
- How to access better medical care
- How to teach our client to self exam/give us more details about their disease
- A doctor or nurse who has provided care to a person with d.d. to discuss preventative health

General health information (2)

- More of this information presented to other groups supporting intellectual disabled individuals
- More on health

Educating medical profession (2)

- How to educate medical profession
- Need to influence medical curriculum to ensure doctors are more knowledgeable of aging with developmental disabilities

Herbal medications (1)

- The attributes (if any) on herbal remedies...since many family members want their family members to take these herbal meds

Planning (1)

- Retirement planning

Advocacy (1)

- Systemic advocacy

Outreach (1)

- How to reach and help those not supported by agencies or have no families/significant others

Housing (1)

- What are we doing in our province for aging, disabled that require housing outside the A.C.L. due to health

Question Five: General comments.

Of the 37 respondents, 59.46% (22) made comments. All comments can be summarized as follows:

Comments regarding information presented (11)

- Great info.
- Good info. Thanks!
- Very informative
- Very knowledgeable presenter.
- Excellent speaker-very useful information for reference
- A very informative introduction to people aging
- It was very interesting and informative
- Informative an asset for me in a front line position. Thank you.
- Extremely well-planned, informative hour!, excellent speaker, excellent location, excellent handouts, thank you
- Great job. Lots of information.
- Very useful info

Comments regarding presentation in general (10)

- Excellent opening session!

- Excellent!
- Extremely well-planned, informative hour!, excellent speaker, excellent location, excellent handouts, thank you
- Great presentation
- Great job!
- Great job! Thanks for coming.
- Great job. Lots of information.
- Enjoyed the presentation overall
- Entertaining
- Looking forward to tomorrow's presentations

Thank you (6)

- Thank you for sharing with us!!
- Informative an asset for me in a front line position. Thank you.
- Extremely well-planned, informative hour!, excellent speaker, excellent location, excellent handouts, thank you
- Thank you for hosting this workshop!
- Great job! Thanks for coming.
- Good info. Thanks!

Handouts (2)

- Extremely well-planned, informative hour!, excellent speaker, excellent location, excellent handouts, thank you
- Handout regarding Dilantin would be helpful – give actual website addresses

Facility and organization (1)

- Extremely well-planned, informative hour!, excellent speaker, excellent location, excellent handouts, thank you

Need to advocate for curriculum changes (1)

- Need to influence medical curriculum to ensure doctors are more knowledgeable of aging with developmental disabilities

Resource provided (1)

- The Ontario Gerontology Society does “memory book” workshops and could be a very useful resource to use

FRIDAY MARCH 31, 2006

“Aging and Developmental Disabilities: Inclusive Communities – Planning and Best Practices”

Of all 76 participants attending the Friday workshop, 68.42% (52) filled out an evaluation. The responses to the ten evaluation questions were reviewed and categorized under main themes for the report. Admittedly, some interpretation was required. I apologize, in advance, for any attribution that may be perceived as erroneous.

Question One: Where do you work?

In response to this question, 63.46% (33) of respondents work in the city of Thunder Bay, 30.77% (16) work in the region of Thunder Bay, 3.85% (2) are retired but reside in Thunder Bay, and 1.92% (1) work in both the region and city of Thunder Bay.

Question Two: Primary role.

In response to this question 46.16% (24) of respondents indicated that their primary role was management, 40.39% (21) indicated direct support worker, 3.85% (2) indicated self-advocate, 1.92% (1) reported family, 1.92% (1) reported facilitator, 1.92% (1) indicated board member, 1.92% (1) reported retired electrical teacher, and 1.92% (1) did not specify.

Question Three: Overall, how would you rate the workshop?

Overall, 69.23% (36) of respondents rated the workshop as very good, 17.31% (9) rated it as excellent, and 13.46% (7) rated it as good. No one rated the workshop as fair or poor.

Of the 52 respondents, 30.77% (16) made comments. These comments can be summarized as follows:

Comments regarding the information presented at the workshop (9)

- Excellent variety of information
- A good variety of speakers and topics
- Very informative
- Very informative
- Very Informative!
- Great resource and networking opportunities
- It was quite knowledgeable especially for someone that is new to this area of the human services field
- Learned many new things as well as networked with other agencies to get ideas on similar issues
- I found the material covered related to where we're heading

General comments (4)

- Went well!
- This type of workshops make things happen for everyone
- Good organization
- Good ideas, lots of discussion and honesty

Comments regarding the opportunity to network (2)

- Great resource and networking opportunities
- Learned many new things as well as networked with other agencies to get ideas on similar issues

Comments on LHIN presentation (2)

- Good presentation – update on policies – funding that maybe in place and governmental
- not sure how LHIN fit in

Need for the presence of both ministries (1)

- We need both ministries present

Question Four: Did the workshop address the outcomes as identified?

In response to this question, 88.46% (46) of respondents indicated that the workshop addressed the outcomes as identified, 5.77% (3) were unsure, 3.85% (2) reported yes with a disclaimer of most or some, and 1.92% (1) left this question blank.

Of the 52 respondents, 26.92% (14) made comments. These comments can be summarized as follows:

General comments (3)

- Good insight!
- Enjoyed the views of others in the field. Lots of networking achieved.
- It's an ongoing process

Hoped for more detailed information (2)

- It covered issues not as deeply as I had hoped
- I hoped it would have been more detailed.

Wasn't what they were anticipating (1)

- I thought it was a teaching on palliative care would be included for end of life care

Organization (1)

- Needed to highlight/incorporate 'aging' information last night into today's presentation

Housing (1)

- People are being placed in housing that is not suitable, they do not always choice – where to live??

Question Five: Please rank each session by circling the appropriate number.

In regards to the overall program, 57.69% (30) indicated very good, 23.08% (12) indicated excellent, 15.38% (8) reported good, and 3.85% (2) left this question blank.

In regards to the keynote presentation, 48.08% (25) indicated very good, 36.53% (19) indicated excellent, 9.62% (5) reported good, 1.92% (1) indicated fair, and 3.85% (2) left this question blank.

Regarding the North West Local Health Integration Network Presentation, 40.38% (21) indicated good, 28.85% (15) indicated very good, 13.46% (7) reported fair, 11.54% (6) reported excellent, 3.85% (2) left this question blank, and 1.92% (1) indicated poor.

For the panel discussion, 46.15% (24) indicated very good, 28.85% (15) indicated good, 13.46% (7) reported excellent, 7.69% (4) reported fair, and 3.85% (2) left this question blank.

In regards to the video, 34.61% (18) indicated very good, 28.85% (15) indicated good, 26.92 reported excellent, 3.85% (2) reported fair, 3.85% (2) reported poor, and 1.92% (1) left this question blank.

Regarding the small group discussions, 42.31% (22) indicated excellent and 42.31% (22) indicated very good, 13.46% (7) indicated good, and 1.92% (1) left this question blank.

Regarding the large group discussion, 51.92% (27) indicated very good, 23.08% (12) indicated excellent, 21.16% (11) indicated good, 1.92% (1) reported fair, and 1.92% (1) left this question blank.

In regards to the agency displays, 48.08% (25) indicated very good, 34.61% (18) indicated excellent, and 17.31% (9) indicated good.

Questions Six: What did you find most valuable about today's workshop?

Of the 52 respondents, 92.31% (32) answered this question. These comments can be summarized as follows:

Small group discussions (13)

- Small group discussion “life enrichment through activity”
- The small group discussion
- Good cross-section of participants – small group topics quite comprehensive – Roy Brown made some insightful points – quality of life shouldn't be stepped on in the name of normalcy
- Small group discussion and networking
- The opportunity to network. Identifying and discussing challenges in services this population and considering possible future solutions
- Small group discussion on end of life care – was able to network with another agency
- I found the group discussions valuable
- The small group discussion
- Small group discussion – hope agency works toward end of life planning
- Discussions
- Group work
- I enjoyed the small working group
- Identifying future needs – info - training, collaboration

Networking (13)

- Opportunity to meet people from different organizations
- Hearing different perspective for different service providers – networking opportunity!
- Networking-fresh ideas
- The networking
- Dr. Roy Brown's lecture and networking with other professionals
- Networking – finding out what's going on elsewhere
- Small group discussion and networking
- The opportunity to network. Identifying and discussing challenges in services this population and considering possible future solutions.
- Hearing different stories, networking
- The opportunity to network with others
- Small group discussion on end of life care – was able to network with another agency
- Networking
- Networking

Keynote presentation (12)

- Roy Brown was an excellent speaker
- Dr. Roy Brown-very knowledged man

- Dr. Brown's presentation was great – longer would have been great
- Good cross-section of participants – small group topics quite comprehensive – Roy Brown made some insightful points – quality of life shouldn't be stepped on in the name of normalcy
- Dr. Roy Brown's lecture and networking with other professionals
- Being able to listen to Dr. Brown
- Dr. Brown – would have appreciated better sound system...a bit soft
- Dr. R. Brown would have liked to have listened to him more.
- Dr. Brown's lecture
- Roy Brown was an excellent speaker – good blend of academic/practical application
- Storytelling examples – show humanistic values views to consider on the people we are supporting for their lifestyle of support in all their domains. To provide their quality of life for their quality of service to meet their individual needs
- Dr. Brown's session was excellent

Hearing about the perspectives and experiences of other agencies (7)

- Hearing about programs, stories, goals from other agencies (especially from out of town)
- Talking with others from other agencies and where there agencies are going
- Hearing different perspective for different service providers
- Many ideas voiced, also, everyone has barriers
- Networking – finding out what's going on elsewhere
- Hearing different stories, networking
- Talking to people from other agencies about their successes and challenges

Comments regarding information presented at workshop (6)

- Lots of practical info to take back to worksite
- I feel more confident as I gathered info on where we're heading towards
- The LHIN presentation was quite interesting. In general, I learned a lot from the workshop overall.
- Information/research shared with us today
- New info
- Info on those organizations or associations that can be accessed for support

Hearing the voice of the region (2)

- Hearing from others in the region re: common issues
- Hearing about programs, stories, goals from other agencies (especially from out of town)

Notion of solving problems at a local level (2)

- Solving problems at a local level
- That a lot of problem solving should start at local level with various agencies

Cross-section of participants (2)

- Good cross-section of participants – small group topics quite comprehensive – Roy Brown made some insightful points – quality of life shouldn't be stepped on in the name of normalcy
- Variety of people from all areas and experience

General comments (2)

- Many things!
- Broad thinking

Panel discussion (1)

- Fostering change at the local level. 3 different outlooks on the topic.

NW LHIN presentation (1)

- The LHIN presentation was quite interesting. In general, I learned a lot from the workshop overall.

Question Seven: What did you find least valuable about today's workshop?

Of the 52 respondents, 71.15% (37) answered this question. Of these 37 respondents, 27.03% (10) indicated that nothing was 'least valuable' in this presentation. Some of these respondents made additional comments. All comments can be summarized as follows:

NW LHIN presentation (12)

- LHIN presentation was well spoken/presented, didn't get a clear answer to how it will affect the agencies in attendance
- LHIN presentation – interesting but not focused enough to be useful
- NW LHIN Presentation
- LHIN – too political
- LHIN presentation
- Pushing the LHIN system – did not stay to be on panel discussion. Not sure this will benefit our services users. Felt she was trying to sell the concept.
- NW LHIN – query of value to CCL agencies
- The LHIN presentation (still new not a lot of answers)
- The LHIN presentation
- LHIN's, very informational, but no answers, I felt it took time away from key speakers and networking opportunities
- LHIN's presentation
- The LHIN Rep did not consider her audience, nor was she prepared to answer specific questions related to developmental disabilities

Video (7)

- Unfortunately the video was drowned out at lunch – worth seeing again though
- Playing the video during lunch I felt was unproductive as the majority of the people were talking. Don't get me wrong it seemed like a good video and I really enjoyed getting an "A"
- The video may very well have been very good but unfortunately it got "squeezed out"
- The video
- The art of possibilities
- Although the video was excellent, I found my attention span was lagging at that point due to the length/volume of previous presentations in a.m.
- The video

General positive comments (3)

- I think everything is valuable, depends on how this is applied
- Everything was valuable
- Only attended in the afternoon. It was valuable – good networking

Small group discussions (3)

- Small group discussion with 2 groups – some overlap
- Our small group was too large (2 tables together) and poorly organized
- In our groups – too loud. I could not hear our own participants in the group

Large group discussion (2)

- The large group discussion by its nature is difficult to follow
- Small group responses – lots of repetition – shouldn't have each group report on each - highlights

Lack of time provided (2)

- Too rushed, but on the other hand nothing dragged on.
- Not enough time to network – I work in health would have liked to find out more about work in D.D.

Some aspects lengthy (1)

- Some aspects seemed lengthy

Not all questions answered (1)

- Not all questions were answered. Only the edge of the issue was covered.

Panel discussion (1)

- Panel of discussion

Question Eight: What do you believe the next steps should be to continue the work started today?

Of the 52 respondents, 81.08% (30) answered this question. These comments can be summarized as follows:

Education (18)

- More sessions!
- More seminars and speakers
- Continue to provide educational events
- Having more workshops like this that not only educates service providers but society as a whole
- More training events for face to face dialogue and info sharing
- Keeping others informed
- Coordinating agencies beyond the ‘talk’ stage. Education.
- Expand on topics with another workshop at a later date
- Interagency collaboration and education
- Public education; Ensure needs and possible solutions are articulated to the LHIN’s
- Get out into the community to inform other service providers e.g. doctors, policy makers-ministry
- Passing information down to front line staff-give front line staff opportunity to encourage change one person at a time!
- Make this material and information available to front line staff. Get their input from experience in the homes as well find out what they want to know
- Agencies to fax information and updated information to homes supporting people and adding a comment section for staff input
- As new info comes in let the participants know
- In depth step by step aging issues specific
- Info session on planning for end of life care; steps needed to prepare for and after death (legal, funeral, etc.)
- More education re: change and how to get there

Networking/Partnerships/Collaboration (14)

- Follow through on developing partnerships
- Interagency collaboration and education
- Communication between agencies and sharing ideas
- Continue the cross-agency/services pollination – networking opportunity!
- Funding, working together
- Get the ministries and agencies together to work together
- Partnerships – health and social sciences

- Talk and start with other agencies and really learn how to coordinate services offered. Recognize the real needs and find solutions
- Involve others in change
- We need to have joint board meetings in the North West and eventually involve the LHIN and MCSS
- Future partnership creations – through interagency contacts/networking to address client needs as a whole
- Self advocates to be invited onto committees
- Keeping the networking and communication open between the agencies present at this workshop
- Encourage forums for more and increased networking

Take action on areas identified in small group discussions (6)

- Take the two priorities from each group and implement change
- Take the plan and put it into action
- Build on recommendations from small groups
- Action on some of issues
- Take the topics of the small group discussions and elaborate on resources and how agencies can work together to develop goals, provide education
- Commitment to one or more strategy

Take action in general (3)

- Coordinating agencies beyond the ‘talk’ stage. Education
- Working groups – cross sectoral-multi-level
- Continue to implement the changes and to have a positive attitude toward the growing needs

Record and share information (2)

- Compile info gathered and provide it to the agencies who attended and are involved
- Record and continue to share knowledge and best practices

Need for input from frontline staff (2)

- Make this material and information available to front line staff. Get their input from experience in the homes as well find out what they want to know
- Agencies to fax information and updated information to homes supporting people and adding a comment section for staff input

Develop policies and protocols (2)

- Develop EOLC team, policies and protocols
- Initiation of policies/procedures. Start with small steps at grass roots level

Examine current programs and how to push these forward (1)

- Take a look at our programs...what do we need to push them forward

Getting involved in the transition of the people supported (1)

- Getting involved in the transition of the people we serve as they age

Funding (1)

- Funding, working together

Question Nine: What education topics would you like to see offered in the future?

Of the 52 respondents, 67.31% (35) answered this question. These responses can be summarized as follows:

End-of-life care (4)

- Palliative care – what are the steps that need to be taken
- End of life, wills
- Specific end of life care for this group. Innovation, possibilities
- Dealing with death issues in full

Communication (3)

- Communication
- Counseling, communication, leadership training
- More information on supporting people to live in their community and more on communication at every level

Counselling (3)

- Counselling, communication, leadership training
- Counselling workshops
- How to counsel, building trust with families, consumers with DD

Success stories (3)

- More info on success stories of people living with development disabilities despite aging issue
- Examples of real situations and outcomes involving the aging population with DD
- I like hearing personal-real life stories

Similar educational opportunities (3)

- Similar: Aging and developmental disabilities

- More sharing opportunities – such as the small group discussion
- More of same – offered to more direct support staff i.e. affordable

Transitions (2)

- Transition between school and work; reaching out to parents and helping them to be good caregivers
- Transitioning DD teens into adult services; improving the finance of DD people

Aging in place (2)

- More information on supporting people to live in their community and more on communication at every level
- Managing changes in health care needs – aging in place needs

Creative solutions (2)

- Solutions/ideas to address needs when no or limited funding is available to provide needed services – especially housing/supportive services for those with aging parents
- Creative solutions that would aid individuals so that they can lead long prosperous lives

Developing partnerships (2)

- How to develop partnerships and “cross board polonization”
- Senior management respecting frontline staff

Education to overcome discriminatory attitudes (2)

- To show people we are all the same
- Overcoming stigmas and stereotypes

How to prepare frontline staff (2)

- What front line staff can do in the individual homes to make it comfortable for individuals also others in the individuals life – family, staff
- How to prepare front line staff for the aging population

Education for caregivers (2)

- Transition between school and work; reaching out to parents and helping them to be good caregivers
- more in-depth info and education for the caregiver and how to support aging individuals

Health (2)

- Health promotion
- Managing changes in health care needs – aging in place needs

Planning (1)

- Planning

Alternate educational resources (1)

- Possible videos/DVDs if a person(s) is unable to attend seminars!

Available services (1)

- Workshop(s) specifically for frontline staff to educate everyone on what services are available to the people we support (no more excuses that staff “didn’t realize that “that” was possible-you hear that all the time)

Improving financial resources (1)

- Transitioning DD teens into adult services; improving the finance of DD people

How to educate the public (1)

- How self advocates can help educate public e.g. video, presentations

Aging (1)

- Aging population

Specific disabilities (1)

- More focused information on specific conditions i.e. downs, autism etc.

Leadership training (1)

- Counselling, communication, leadership training

Information about ministry (1)

- More about MCSS

Question posed (1)

- Should we survey all organizations? – including those who may not have been present?

Question Ten: General comments.

Of the 52 respondents, 86.54% (45) made comments. The comments can be summarized as follows:

General positive comments (26)

- All was fine. Fruit would have been nice at opening
- No complaints
- All satisfactory
- Good.
- Good.
- Good.
- Well done
- Great!
- Great.
- Overall very good.
- Venue very good, good job CERAH
- Very good
- All of the above were very good.
- Very good.
- Very good workshop. Very smoothly run.
- Excellent
- Excellent
- Excellent
- Excellent job.
- Excellent!
- Excellent! – way to go
- Excellent! Extremely well organized. Charlene is extraordinarily efficient!
- All listed above were great!
- All aspects of the workshop were excellent. The displays were an extra bonus and was informative
- Refreshing
- Enjoyable workshop – interesting views and topic of today’s aging problem and future problems

Food (12)

- Great food, good turn-out and good cross-section
- Good food, facility, well run operation
- Registration – well organized; Facility – spacious, comfortable; Food – great coffee (a must) – lunch great – perhaps more cold drinks – healthy choices instead of heavy desserts
- Food/facility – ok; need to keep on schedule
- Good service – sandwiches could be served to the menu
- Excellent location, food etc.
- Beautiful facility, food was great

- More choice for morning snack (not just muffins) would be nice as not all of us eat muffins – perhaps some healthier choices
- Veggie items for those who don't eat meat
- Food not bad but there wasn't enough – I was at back of the line and there was not much to choose from; facilitators/volunteers good – organized
- All was fine. Fruit would have been nice at opening

Planning/Organization (11)

- Well organized!
- Good food, facility, well run operation
- All well organized
- Very good workshop. Very smoothly run.
- Registration – well organized; Facility – spacious, comfortable; Food – great coffee (a must) – lunch great – perhaps more cold drinks – healthy choices instead of heavy desserts
- Food not bad but there wasn't enough – I was at back of the line and there was not much to choose from; facilitators/volunteers good – organized
- I think Charlene did an outstanding job – she deserves a lot of credit for today's success – her hard work and attention to detail were much appreciated.
- Excellent! Extremely well organized. Charlene is extraordinarily efficient!
- Food/facility – ok; need to keep on schedule
- Dr. Brown and Leslie Udell did not have enough time allotted to them. It would have been great if key speakers had more time to share their information
- Allowing longer breaks to allow networking would be good

Facility (8)

- Good food, facility, well run operation
- Registration – well organized; Facility – spacious, comfortable; Food – great coffee (a must) – lunch great – perhaps more cold drinks – healthy choices instead of heavy desserts
- Excellent location, food etc.
- Beautiful facility food was great
- Venue very good, good job CERAH
- In our groups – too loud. I could not hear our own participants in the group
- Good/facility – ok; need to keep on schedule
- Spread out tables

Displays (2)

- All aspects of the workshop were excellent. The displays were an extra bonus and was informative
- Include space for non-paying exhibitors e.g. Alzheimer, Elder Abuse

Participant turn out (2)

- Great food, good turn-out and good cross-section

- No ministry

Thank you (1)

- Thank You!