SECAID

Simcoe Education Committee for Aging
& Intellectual Disabilities

Event Organized by

- Simcoe Community Services
- Coleman Care Centre
- Community Living Association for South Simcoe (CLASS)
- Jarlette Health Services –Leacock Care Centre
- Preferred Health/Leisureworld Orillia
- Camphill
- VON
- Alzheimer's Society
- North Simcoe Muskoka Community Care Access Centre
- Bob Rumball – Home for the Deaf

TERMS OF REFERENCE FOR SECAID

(SIMCOE EDUCATION COMMITTEE FOR AGING
& INTELLECTUAL DISABILITIES)

Background:

- The Committee evolved as a response to the need in Simcoe County for an organized approach to the issue of education for those working with people who are aging with a intellectual disability as a primary focus. The establishment of the SECAID was developed from a strategic direction at the Central East Region Aging and Intellectual Disabilities provincial conference November 27 & 28, 2006.

Membership to the Committee:

- Membership representation comprises of agencies of companies in Simcoe County providing care to persons who are aging and have intellectual disabilities.

Role the Committee:

- The overall role of the committee is to educate those working with Aging individuals with intellectual disabilities in Simcoe County.

Responsibilities of the Group:

- Identify education needs on Aging and Intellectual Disabilities in Simcoe County.
- Establish concrete action plans for education initiatives that will benefit those who are working with Aging and Intellectual Disability clients.
- Explore new initiatives which will support the learning process of SECAID network and the larger community.

- Identify funding opportunities to assist with education and training.
- Collaborate with local partners for learning opportunities.
- Ensure there is effective communication that fosters collaboration with all partners/care providers including Central East Aging and Disabilities Committee.

- All committee members volunteered their time, with the support of their respective agencies. In order for the Marketplace to take place, the Committee required a grant or donations to host the event. The Committee sent a letter to Casino Rama requesting help to sponsor the event. Casino Rama sent back an application form asking the Committee to complete it and send back to them.

Objectives of the Marketplace

- To acquaint Simcoe County agencies (Board members and staff) with the resources available across all service sectors involved with this target group (Developmental Services, Mental Health, Long-Term Care).
- Create opportunities for networking, collaboration and understanding across service sectors and between agencies and families.

The Marketplace Will:

- Attract participants with "well known speakers" who will address new developments, research and collaborative models.
- Present information displays and demonstrations.
- Offer participants an opportunity to "shop" for services matching their client's needs based on case studies.

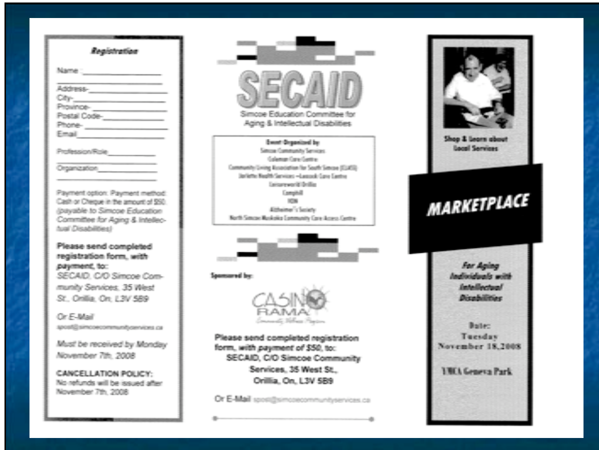
Participants Will:

- Participants will have more information about available resources and how to access those needed for the aging individuals/seniors.
- Participants will also identify potential future contacts useful for planning and have seen practical demonstrations and cross-sectoral approaches.

- The Simcoe Education Committee for Aging and Intellectual Disabilities (SECAID) received $1500 from Casino Rama, to assist in sponsoring the Market Place Workshop that was held on November 18th, 2008, at the Geneva Park Conference Centre.

Invitations were sent out to the following groups:

- Mental Health
- Community & Social Services
- Agencies serving individuals with intellectual disabilities
- Residential Services
- Community Care Access Centre
- Acute Care, Physicians
- Long-term Care Homes
- Adult Day Services
- Family/Adult Support Services
- Aboriginal Services
- Francophone Services and
- Families and clients with intellectual disabilities



Registration

Name :
Address-
City-
Province-
Postal Code-
Phone-
Email

Profession/Role
Organization

Payment option: Payment method: Cash or Cheque in the amount of $50. (payable to Simcoe Education Committee for Aging & Intellectual Disabilities)

Please send completed registration form, with payment, to:
SECAID, C/O Simcoe Community Services, 35 West St., Orillia, On, L3V 5B9

Or E-Mail
spost@simcoecommunityservices.ca

Must be received by Monday November 7th, 2008

CANCELLATION POLICY:
No refunds will be issued after November 7th, 2008

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Leisureworld Orillia
Camphill
VON
Alzheimer's Society
North Simcoe Muskoka Community Care Access Centre

Sponsored by:
CASINO RAMA

Please send completed registration form, *with payment of $50,* to:
SECAID, C/O Simcoe Community Services, 35 West St., Orillia, On, L3V 5B9

Or E-Mail spost@simcoecommunityservices.ca

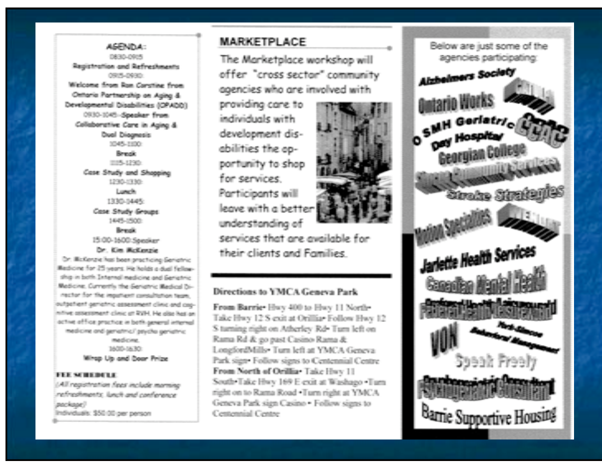
Shop & Learn about Local Services

MARKETPLACE

For Aging Individuals with Intellectual Disabilities

Date:
Tuesday
November 18,2008

YMCA Geneva Park



AGENDA:
0830-0915
Registration and Refreshments
0915-0930:
Welcome from Ron Corstine from Ontario Partnership on Aging & Developmental Disabilities (OPADD)
0930-1045-**Speaker from Collaborative Care in Aging & Dual Diagnosis**
1045-1100:
Break
1115-1230:
Case Study and Shopping
1230-1330:
Lunch
1330-1445:
Case Study Groups
1445-1500:
Break
15:00-1600-Speaker
Dr. Kim McKenzie
Dr. McKenzie has been practicing Geriatric Medicine for 25 years. He holds a dual fellowship in both Internal medicine and Geriatric Medicine. Currently the Geriatric Medical Director for the inpatient consultation team, outpatient geriatric assessment clinic and cognitive assessment clinic at RVH. He also has an active office practice in both general internal medicine and geriatric/ psycho geriatric medicine.
1600-1630:
Wrap Up and Door Prize

FEE SCHEDULE
(All registration fees include morning refreshments, lunch and conference package)
Individuals: $50.00 per person

MARKETPLACE

The *Marketplace* workshop will offer "cross sector" community agencies who are involved with providing care to individuals with development disabilities the opportunity to shop for services. Participants will leave with a better understanding of services that are available for their clients and Families.

Directions to YMCA Geneva Park

From Barrie• Hwy 400 to Hwy 11 North• Take Hwy 12 S exit at Orillia• Follow Hwy 12 S turning right on Atherley Rd• Turn left on Rama Rd & go past Casino Rama & LongfordMills• Turn left at YMCA Geneva Park sign• Follow signs to Centennial Centre
From North of Orillia• Take Hwy 11 South•Take Hwy 169 E exit at Washago •Turn right on to Rama Road •Turn right at YMCA Geneva Park sign Casino • Follow signs to Centennial Centre

Below are just some of the agencies participating:

Alzheimers Society
Ontario Works
OSMH Geriatric Day Hospital
CCAC
Georgian College
Stroke Strategies
Motion Specialties
Jarlette Health Services
Canadian Mental Health
VON
York-Simcoe Behavioral Management
Speak Freely
Barrie Supportive Housing

- Having all 28 service agencies in one central room was very successful, the energy in the room was very positive. There was plenty of enthusiasm and a vast exchange of information.
- The service agencies were very excited in being part of the Market Place workshop, they donated money and prizes etc which allowed the Committee to purchase certificates to raffle out. Also participating agencies donated sweatshirts, bags, lifts etc.

- Jarlette Health Services also prepared green gift bags to give out to all workshop participants. These bags were filled with the donations received (i.e.: pens, paper, snacks) and were also used for participants to put their brochures in.
- The seventy (70) workshop participants who registered left their email addresses for an evaluation of the event to be mailed to them. The evaluation forms indicated that they had learned important information from the speakers. A $50 gift certificate was drawn for one person who returned their evaluation.

Some of the comments noted in the evaluation forms were:

- A great wealth of information.
- Guest speakers were informative and provided valuable information for me to bring back to my workplace.
- Dr. McKenzie was fabulous.
- Reassuring the expectation in community is to work in partnership, reduce duplication, share information and be supportive to each other.
- Job well done.

The guest speakers were:

Dr. Kim McKenzie, a practicing specialist on both Internal and Geriatric Medicine.

Ron Corstine from the Ontario Partnership on Aging and Developmental Disabilities.

Marc Simpson and Anna Lee King from the Collaborative Team. They represented the Dual Diagnosis Unit and Geriatric Services program at the Penetang Mental Health Centre.

Case Study #1 - Jim

Jim a 54 year old man who does not use words to communicate. He has been diagnosed with Downs Syndrome and a developmental delay. Jim lived with his family until the age of 28 at which time he moved Into a group home setting (24 hour care). Over the years as his mother aged, she had difficulty providing the care Jim required, she received little assistance from his siblings.

Jim needs assistance completing hygiene and dressing routines. If not assisted, Jim will layer his clothing sometimes wearing two or three sets of pants and several shirts. He is not able to determine weather appropriate clothing, which can be very dangerous in both summer and winter. Jim will take off his clothes out of his dresser and closet and hide them sporadically around his room and the rest of the house. He has not been known to cut his clothes when he has access to scissors. Jim does not read, has limited street safety skills and little to no understanding of money.

Jim appears to enjoy flushing items in the toilet. He has been known to flush paper towels and clothing causing many plugged toilets and floods. Jim wears glasses, but will often hide them away or try to throw them into the garbage. His eyes are very sensitive to the light and he is prone to eye infections. Medically, there are a number of issues that staff are aware of; Jim suffers from poor circulation in his legs resulting in sever swelling. He has been diagnosed with arthritis in his knees, backs and legs. His feet are severely callused.

Jim participated in an adult day program and periodically goes on work crew (cutting grass). He likes to make his own lunch but requires some assistance. Over the past several months Jim seems to be somewhat disoriented. His overall energy level and desire to socialize has greatly diminished. Residential staff have noticed that he has started leaving the house unaccompanied and his sleeping habits have changed (has been sleeping in a chair at night with no blankets). At the day program, he has been unable to complete routines that are familiar, he has been found in the ladies washroom and he tends to be "spaced out".

Case Study #2 - Julia

Julia and her family are supported by the Family Support Program. Family support have been involved with this issue since Julia was diagnosed with a brain tumor at the age of eight. She has continued to receive weekly/monthly treatment related to the tumor at Sick Kids in Toronto. The tumor resulted in the loss of vision, developmental delays and the loss of the ability to taste, and sense hot/cold.

Julia is now a student at Joan of Arc Secondary School in Barrie. She has not attended school for the past 3-4 weeks due to the onset of seizures (grand mal) and Sick Kids determined they were unable to drain the tumor, which is the first time in 13 years thy have not gotten fluid. This is not a good prognosis. An MRI was ordered and they have been treating her with anti-seizure medication.

Julia now requires a very high level of eyes on supervision and support in case of a seizure. She cannot be left alone and there does not appear to be any warning signs of precipitating the seizures.

Julia's mom has just been diagnosed with Stage 4 Advanced Breast cancer which has spread into her bones causing her to easily break ribs and puts her at risk should Julia have a seizure and break some of her bones because of falling.

Julia's step-dad has Chron's disease which has flared up and he is quite ill as well. He works as often as he can.

Family is requesting SCS to assist with providing or locating a place when Julia can live and be supported appropriately.

Case Study Exercise

Each organization wrote a sample case study pertaining to the organization they were representing. These organizations were from the Developmental Services Sector, Mental Health, Community Living and the Long Term Care Sector.

The Committee ensured that participants were seated with people from other organizations to maximize their learning experience and gain new insights.

Action Plan

- Referral to developmental service coordination committee
- Referral to ODSP (financial) for mandatory necessities
- Referral to SSAH special services at home
- Application for passport program
- Apply to CCAC - nursing needs (24 hr care), home making
- OT
- respiteservices.com
- Referral to CNIB
- Epilepsy Ontario
- Julie transitioning from Sick Kids to another care team.

Case Study #3 - Barbara

Barbara is a 42 year old women living with Downs Syndrome and a suspected form of dementia. Barbara resides with her mother and stepfather in a farmhouse in Innisfil. Barbara's mother is currently experiencing caregiver burnout as she is the primary caregiver and receives little to no support from other family members. Barbara is non verbal, not having spoken in over several years. She also requires assistance with activities of daily living and only allows her mother to assist with her bating routine.

One challenge that Barbara and her mother face is how slow it takes Barbara to perform any task. It often takes Barbara two and a half hours to eat lunch and it is difficult for Barbara to walk anywhere of distance because of her slow pace. The family does have support from CCAC and has a PSW that comes in several times a week. Barbara is starting to refuse care from anyone other than her mother and is also refusing to get out of bed, often staying in bed for two to three days.

Case Study #4 – Jack and June

Jack is a 79 year old gentleman who lives on and off with his ex-wife, June. June is about 10 years younger than Jack and in better physical health than her husband. They are both developmentally delayed. They divorced years ago reportedly for financial reasons to maximize their benefits. June often threatens to leave for good, but rarely stays away for long. Over the last several months Jack has been admitted many times to hospital related to injuries from falling, poorly managed diabetes and seizures. Jack and June have been living independently in a tiny apartment for several years wit 60 birds they adore.

They have the support of a kindly elderly neighbour, members of their church for rides and meals, and local soup kitchen workers. They have hired Meals and Wheels and Helping hands for personal care in the past but failed to pay the bills. Neither of them have family and there are no power of attorney documents.

Jack is marginally more impaired than June. Jack presents confused, has poor memory and judgment. He is also incontinent. June cannot manage his care which includes personal hygiene, keeping track of multiple medications and blood monitoring for his diabetes. Until recently Jack was able to walk with the aid of his walker to the soup kitchen daily to get lunch and socialize. His last hospitalization was the result of a serious brain injury. Jack has been left more confused, weakened and unable to walk in the soup kitchen.

The Community Care Access Centre was contacted while in hospital to provide supports and information on placement to long term care facility. Both Jack and June flatly refused to be assessed for alternative living arrangements. They were accepting of personal support services to assist with bathing and meal preparation, physiotherapy for balance and mobility, and nursing to monitor Jack's medications and diabetes. Before long the supports of the Community care Access Centre were not sufficient to support this couple safely in the community.

Jack's health continued to decline and he was hospitalized again. He agreed to go to a retirement home when discharged because his wife had left him again, but two days after settling in he returned to live with his wife and birds. Upon meeting with CCAC in their home June is adamant that they will continue to live together in the apartment. They were both unkempt and the apartment overly cluttered with bird poop everywhere. Neighbours have called the CCAC and public health concerned about the safety and well being of the couple and their pets.

Problems: med management, personal care, future planning, POA, mobility equipment, IADL management (paying bills), frequent hospitalizations and declining health/falls with numerous injuries, limited $, insufficient support, complex medical issues, no competent decision makers.

Case Study #5 - Beth

Beth is a 71 year old female who is deaf and suffers from chronic brain syndrome and paranoid schizophrenia. She attended the School for the Deaf for 10 years but has very little to no communication skills and will mimic gestures. Currently, she lives with her niece due to lack of family support from Beth's brothers and sisters. Her niece is looking for alternate living arrangements because she is getting remarried to a man who has 2 young children.

Beth exhibits frequent mood swings where she will strike out at any individual around, throw objects, and remove clothing at inappropriate times. As well, in the past 6 months her health and ambulation is deteriorating after a fall in the kitchen.

CCAC has provided personal support workers with one staff in particular on a consistent basis. This staff has developed a relationship with Beth and when a new personal support worker enters her home she had behaviours.

Her niece is concerned about Beth's behaviours and where an appropriate place for her to live.

What suggestions and support would you offer to Beth?

Case Study #6 - Jason

Jason is a gentleman who is 53 years old and has Downs Syndrome. He has been supported by an agency for the last 15 years. Currently he lives in a very clustered apartment setting. He had always had serious anxiety issues as well as obsessive compulsive tendencies. He has difficulty interacting with others and really prefers to live alone.

In the last couple of years staff have noticed a deterioration with Jason. They have noticed his obsessive compulsive behaviours have been increasing, he refuses to leave the apartment with anyone else, but will sometimes leave on his own and attempt to cross the road with heavy, fast moving traffic. He refuses to use dishes (eats off plates and plastic cutlery, will not prepare his own food (mother comes in and prepares the meals) and refuses medical appointments to the point that he has not seen a physician in three years. Even though Jason complains about his knees when climbing stairs he violently refuses to see any physician.

Jason sits and stares out his window all day and will not allow CCAC worker to enter his apartment to assist with bathing. Consequently his mother has to help him.

Jason's mother is very elderly and cannot continue to care for him as she wants. She wants to move closer to his apartment so she can help. Jason has been offered many different residential options and most recently turned down a group home vacancy.

Staff are concerned about the fact that his independent living skills have deteriorated so much and will only accept the help of his mother who may soon be gone. Staff have suggested long term care homes with the mother, but she wants him to stay where he is and she is willing to accept the risks.

What supports can be offered to keep Jason safe?

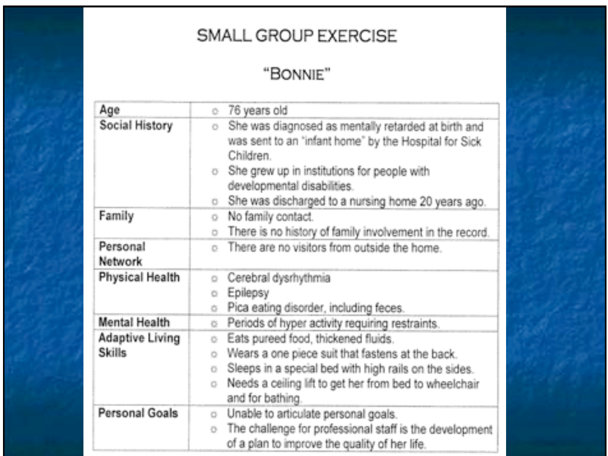
Action Plan

- Increase current agency staff support and ask what he wants (possible change of staff)
- Find doctor to see if they will make house call
- Diagnosis is Alzheimer's
- Connect with Alzheimer's society to first link for and educate himself if mother and staff
- Helping hands re: meals on wheels & friendly visitor program
- See if CCAC worker can be changed, could be he just doesn't like him
- Referral need to have hearing assessment
- Referral to Bayview Dual Diagnosis due to increased anxiety, OCD, depression
- Change apartment location due to mobility and reduce traffic

SMALL GROUP EXERCISE

"ALBERT"

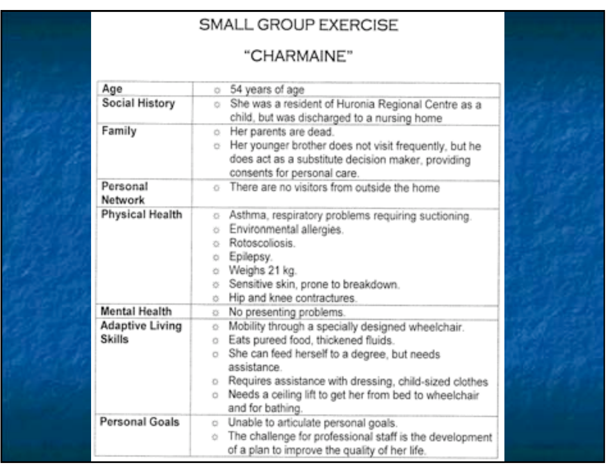
Age	○ 80 years old
Social History	○ As a young adult, Albert was arrested for a property crime but was found unfit to stand trial because of intellectual disability. He spent 20 years at the Mental Health Centre in Penetang before he was sentenced to "time served" and released to a group home. ○ He reports being physically and sexually abused at the PMHC & is afraid of being sent back to an institution. ○ Albert moved out of the group home into a private boarding home.
Family	○ No family involvement currently. ○ Family contact was lost during the time he was incarcerated.
Personal Network	○ Involved in a local church, passes out the church bulletins, accepted by the other church-goers. ○ He likes keeping busy and has a history of doing odd jobs in his neighbourhood, e.g. raking leaves, shoveling show. ○ CCAC comes in twice weekly to bathe him.
Physical Health	○ Losing weight, down to 100 pounds. Reason for weight loss is not clear. ○ He presents as frail. His hands shake. ○ May be incontinent.
Mental Health	○ Chronically depressed ○ Exhibits schizophrenic behaviours. Not clear whether they are due to his own mental state or whether they are "learned" behaviours acquired while at PMHC. ○ Memory appears to be failing recently. ○ He has always had trouble remembering names.
Adaptive Living Skills	○ Needs frequent reminders to wash. ○ Dresses poorly. ○ Smokes ○ Can't cook, use the microwave, etc. ○ Can't tell time ○ Poor attention to personal safety, e.g. has been hit twice by cars while jaywalking.
Personal Goals	○ Wants to live on his own in his own apartment ○ Wants to get married



SMALL GROUP EXERCISE

"BONNIE"

Age	○ 76 years old
Social History	○ She was diagnosed as mentally retarded at birth and was sent to an "infant home" by the Hospital for Sick Children. ○ She grew up in institutions for people with developmental disabilities. ○ She was discharged to a nursing home 20 years ago.
Family	○ No family contact. ○ There is no history of family involvement in the record.
Personal Network	○ There are no visitors from outside the home.
Physical Health	○ Cerebral dysrhythmia ○ Epilepsy ○ Pica eating disorder, including feces.
Mental Health	○ Periods of hyper activity requiring restraints.
Adaptive Living Skills	○ Eats pureed food, thickened fluids. ○ Wears a one piece suit that fastens at the back. ○ Sleeps in a special bed with high rails on the sides. ○ Needs a ceiling lift to get her from bed to wheelchair and for bathing.
Personal Goals	○ Unable to articulate personal goals. ○ The challenge for professional staff is the development of a plan to improve the quality of her life.



SMALL GROUP EXERCISE

"CHARMAINE"

Age	○ 54 years of age
Social History	○ She was a resident of Huronia Regional Centre as a child, but was discharged to a nursing home
Family	○ Her parents are dead. ○ Her younger brother does not visit frequently, but he does act as a substitute decision maker, providing consents for personal care.
Personal Network	○ There are no visitors from outside the home
Physical Health	○ Asthma, respiratory problems requiring suctioning. ○ Environmental allergies. ○ Rotoscoliosis. ○ Epilepsy. ○ Weighs 21 kg. ○ Sensitive skin, prone to breakdown. ○ Hip and knee contractures.
Mental Health	○ No presenting problems.
Adaptive Living Skills	○ Mobility through a specially designed wheelchair. ○ Eats pureed food, thickened fluids. ○ She can feed herself to a degree, but needs assistance. ○ Requires assistance with dressing, child-sized clothes ○ Needs a ceiling lift to get her from bed to wheelchair and for bathing.
Personal Goals	○ Unable to articulate personal goals. ○ The challenge for professional staff is the development of a plan to improve the quality of her life.

SMALL GROUP EXERCISE

"DAGMAR"

Age	○ 60 years old
Social History	○ She grew up at home with her family, attending school in what was then known as "opportunity classes." ○ She has difficulty reading and writing and can not do math, even with a calculator. ○ She married in her late 30's, but the couple was unable to have children. ○ They adopted a girl from an Asian country. She is now out of school, working, and has her own child. ○ Dagmar's marriage ended in divorce. ○ She receives an ODSP pension on the basis of a developmental disability. She also gets a modest support payment from her former husband. ○ Following hospitalization after her stroke, Dagmar was discharged to a retirement home. There was no one at home to care for her.
Family	○ Her parents are deceased. ○ There are regular visits from her brother and her daughter.
Personal Network	○ There are occasional visits from friends. ○ A minister from a local church visits her weekly.
Physical Health	○ Dagmar constantly complains of being in pain. Her history shows long term use of prescribed pain killers. ○ She suffered a stroke 5 years ago, and was able to walk when first discharged from hospital. However, her history shows she has not walked for over 4 years. ○ She has lost the use of her left hand.
Mental Health	○ She appears to be depressed. ○ She has erratic behaviour, frequently weeping and shouting, often asking for help with the pain.
Adaptive Living Skills	○ She has lost weight, now weighing 68 pounds. ○ She is picky about her food, often refusing to eat. ○ She is incontinent. ○ She uses a specially designed wheelchair.
Personal Goals	○ Dagmar wants to return home and live with her daughter.

RESULTS

The case study exercise and shopping for services proved to be a success, some of the comments in the surveys submitted were:

- Great place for networking and learning more about the resources available to help those I work with.
- Really enjoyed the interactive process for case study when looking for resources in the market place – it really was helpful using case study to ask about what resources they provided.
- I enjoyed the day and was able to "network" with individuals I have spoken with on the phone as well as expanding my knowledge of what's out there for seniors and vulnerable populations.

- Evaluation forms were created to receive feedback from workshop participants.
- To encourage people to complete these forms, there was a draw for $50 gift certificates to Tim Horton's.
- As previously noted the comments from these evaluations forms were very positive. People enjoyed the food, they learned valuable information from the speakers and the interaction and shopping for services at the Marketplace was rated as the most "favourite" part of the workshop.

Conclusion

The Market Place workshop was very successful; it was well received considering it was a first time event. The SECAID Committee established what they set out to do, provide information, educate one another and demonstrate what services are available for the aging population with intellectual disabilities.

Aging and Education Needs - Forum

What do you see as the biggest concern regarding aging and individuals with a DD that you serve?

- Lack of acceptance with other residents
- Not accepted by staff due to lack of training
- Resources
- Cross-sector education problems
- DD residents not interested in LTC activities
- Staffing differences between sectors
- Lack of knowledge of future – "what is normal aging process of this population?" No previous information as this is first generation.
- Assessments – not normed to this population, difficult to determine other co-morbid conditions as a result of aging, dementias
- Communication with clients as they age
- Programming – how do we get involved – mental age/functional levels different
- Communication across the continuum of care – group home to acute care
- Providing least restrictive environment
- Different ways of looking at behaviours then with dementia care

What type of info/training do you feel your agency requires most in regards to aging and DD?

- General information, intervention strategies,
- Assessment tools/communication tools specific to this population
- Hasn't been part of their training, especially PSWs
- Difficult to add more education – already so much
- Different level/depth of information depending on discipline
- Need to move education in this area into the curriculum
- Knowing how to identify and communicate a change in the individual; e.g. don't attribute everything to DD; may be demonstrating signs of dementia; need to be able to communicate these "changes" to physician

Does your agency currently have services targeted at meeting the unique needs of individuals with a DD who are aging? What services are lacking?

- From LTC – generally treated the same as other individuals they serve
- Palliative care – all experience same symptoms despite other diagnoses
- Community – supporting clients to remain at home with family etc. – same services as others may need e.g. personal support, day programs, etc

Gaps in Service:

- Doctor's expertise with clients with DD – lack of availability of physician who want to take on this population, similar issues to geriatric population
- Psychiatric supports
- No nursing support in group homes for ongoing competency, day to day management of clients with complex medical needs
- Lack of consistent care plan/communication method across the continuum
- Difficult for acute care staff to develop relationship with client – lack of continuity of staff

What formats of instruction/information would you find most helpful to your organization?

- External consultation – consultant to come in re complex issues, behaviours
- Resource person – needs to be pertinent, when an issue has arisen, ongoing support important, not a one time thing
- More hands on the better
- Case reviews – circle of care to discuss case, real life scenarios
- Classes – need to bring education to them, short in services (1/2 hr. – 1 hr.)
- U-First – on-line
- Needs to be recognized as a specialty

What diagnoses are most prevalent in the population with which you work?

- Down syndrome (may be demonstrating a dementia as well)
- Fragile X
- Meningitis at birth leading to DD
- General developmental delay
- Cerebral palsy
- In community – may not have a proper history, unclear or old diagnosis, never reviewed/reassessed

What disciplines from your agency would most benefit from education on aging and DD?

- All front line staff including dietary, housekeeping, front desk
- Registered staff
- PSW's and activation staff – not trained in DD
- DSWs – not trained in geriatric care
- Management/Administration
- Volunteers
- Other residents/clients, community at large
- Physicians
- Need to remove fear of unknown, develop champions
- Support from other sectors
- Consistency of staff/care – often do better transitioning that what we think they will

What do you feel is the most appropriate setting for individuals with a DD who are aging? What do you see as the ideal environment for such individuals?

- Specific to each individual, hard to generalize
- Secure, safe
- Tolerant, able to respond to individuals needs
- Addresses their social needs
- Activities geared to ability
- Community based, accessible
- Maintained in home environment where possible – "aging in place"
- Consistency in setting – routine, familiarity important – important during time of transition, preparation and communication important
- Ensure Quality of Life
- It is the choice of client/caregiver, choice needs to be respected – may need to balance needs of both – the more variety of options, the better the likelihood of a good fit
- Education needed regarding best practices – partnering between sectors
- Move people who have lived together as a group – maintain familiarity
- Ideally small environment, consistency in staff and programming
- Important to "know" the individual - intimacy

What do you experience as the greatest behavioural problem in elderly individuals with a DD? Hat is the most prominent psychiatric concern in these individuals?

- Attention seeking
- Depression, suicidal ideation
- Behaviours may become more pronounced
- Loud, boisterous – may be a difficult fit in LTC home with other aging residents
- Challenges with comprehension/communication often exhibited as behaviours
- Anxiety related to different populations (dementia)
- Downs syndrome with dementia – start to show signs of dementia "behaviours" change, refuse to eat, resistive to care, incontinent
- As with other individuals with behaviours- need to look at it individually, identify cause, adapt environment to reduce behaviour
- Psychiatric concerns – depression, OCD, dual diagnosis

Dementia is often an ongoing concern in more elderly individuals with a DD; in your experience, are there unique ways that individuals in this population present with dementia?

- ? Coping mechanism e.g. diversion
- Heightened responses
- Important to know mental age/functional level prior to dementia; "What was previous level?"
- Often not enough experience to distinguish between behaviours – "what is causing what behaviour to occur?"
- Transition from home to LTC home – history is key/established routines need to be shared
- Lack of exposure to this population – therefore lack of knowledge of how this may present itself

What are the unique challenges faced in serving elderly individuals with DD in the community?

- Acceptance and understanding
- Tolerance due to lack of education/knowledge of the public, providers
- Isolation
- Working with a family unit not just one individual, caregiver needs care – may be placing a family together in a LTC home
- Levels of "capacity" of individual
- Providing programs that can meet unique needs – physical and mental change
- Social programs that cater to both
- Impact of DD on chronic disease progression – will there be differences in the progression?
- Need to work together to meet unique challenges – ongoing cross sector contact leads to acceptance
- Integration into a single setting/program – seniors, DD, dementia
- In the DS sector – gerontology, dementia, aging – glossed over in the DS program
- Nursing/PSW – gerontology focused, glossed over DD
- Caregivers – understanding progression of a dementia with someone with a DD
- Diagnostic tools available for this population – what is being used?
- Knowledge gap of type of programs available to this population after placement in LTC – i.e. access to day programs in DD sector