Aging & Intellectual Disability: When is it Dementia?

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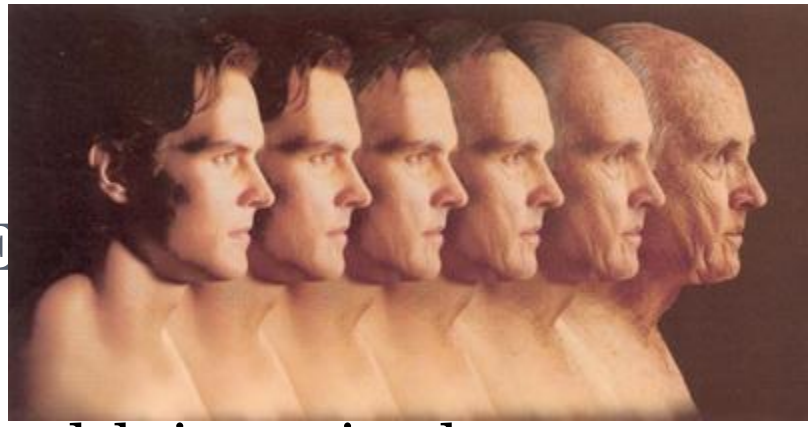
SOME PERSPECTIVE



" aging, that is, growing old, nor should we see it as a health issue in the future, but rather part of the life-course approach. …. Aging starts at birth and throughout the life course we experience changes in our life, and at times we need specialist services and care"

Jane Barratt, International Federation on Aging

What we'll cover

- Important Facts
- Red Flags
- How to intervene
- Cases and Discussion

Resource

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

The **National Task Group** is a collective composed of over 300 agency personnel, academics, government officials, family members, and persons affiliated with various associations and organizations.

The NTG is associated with several organizations (American Academy of Developmental Medicine and Dentistry and the University of Illinois at Chicago's RRTC on Aging and Developmental Disabilities and Health), as well as numerous university centers and national organizations.

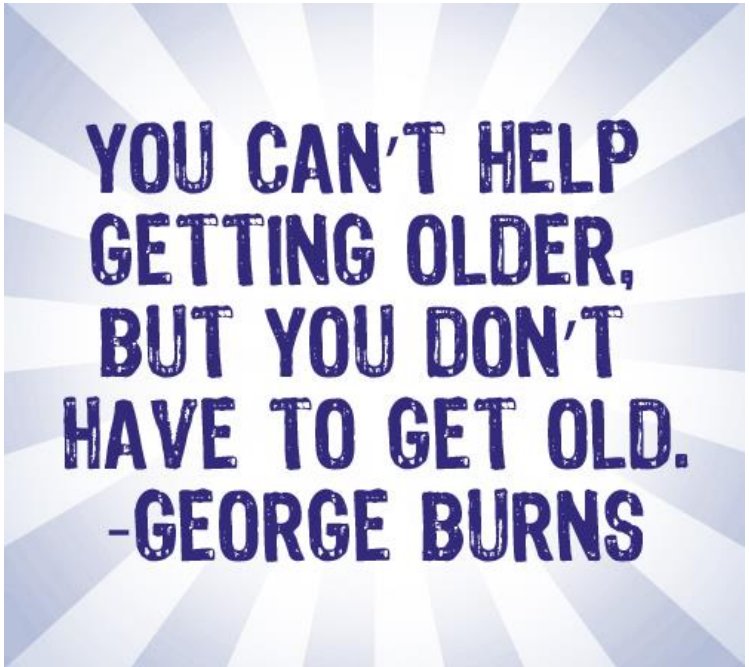
'My Thinker's Not Working'

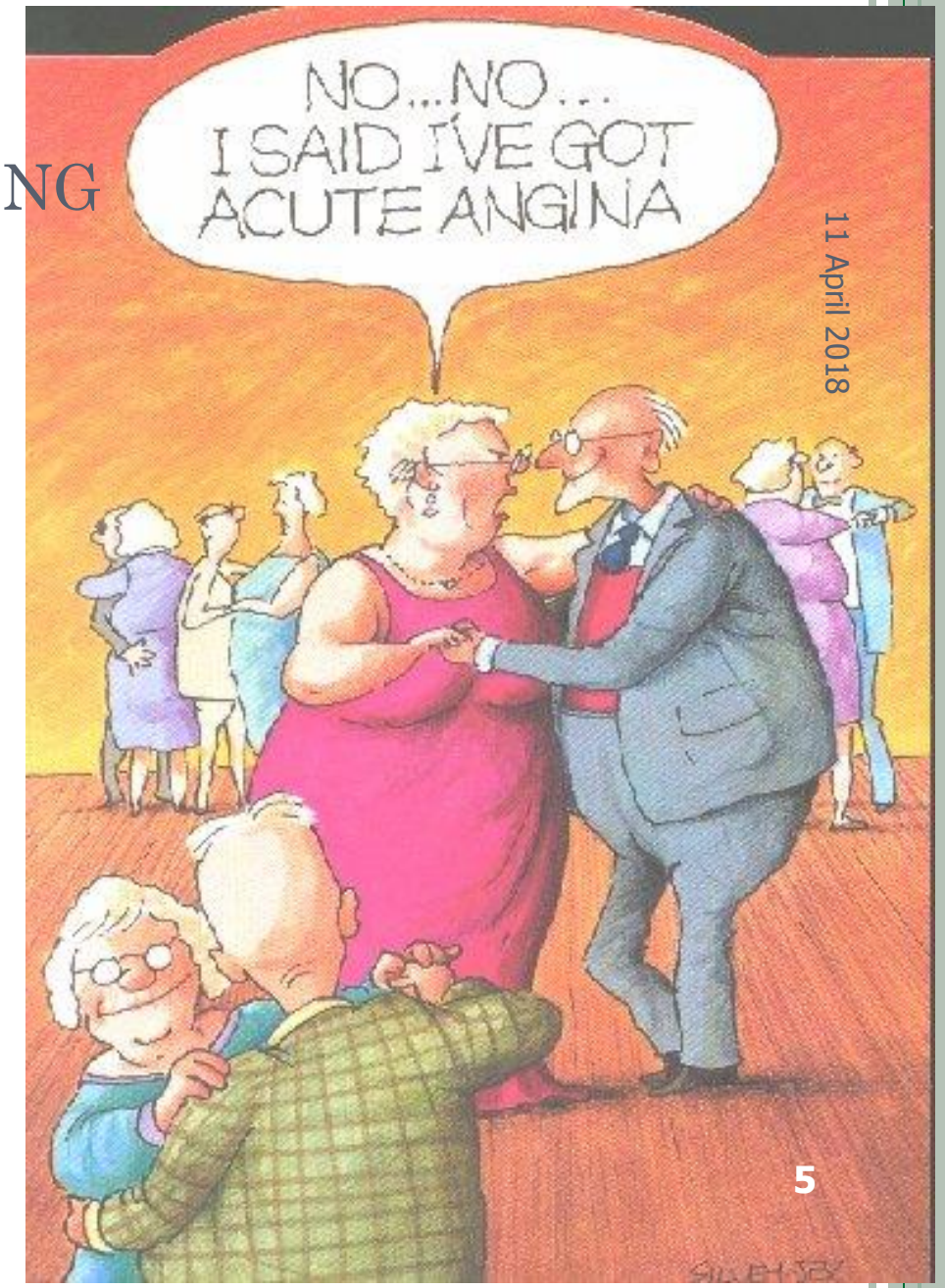
- ✓ To define best practices that can be used by agencies in delivering supports and services to adults with intellectual disabilities affected the various dementias
- ✓ To identify a workable national a 'first-instance' early detection / screening instrument
- ✓ To produce educational materials of use to families, people with ID, and providers of services
- ✓ To further public policy with respect to dementia as it affects adults with intellectual disabilities

www.aadmd.org/ntg

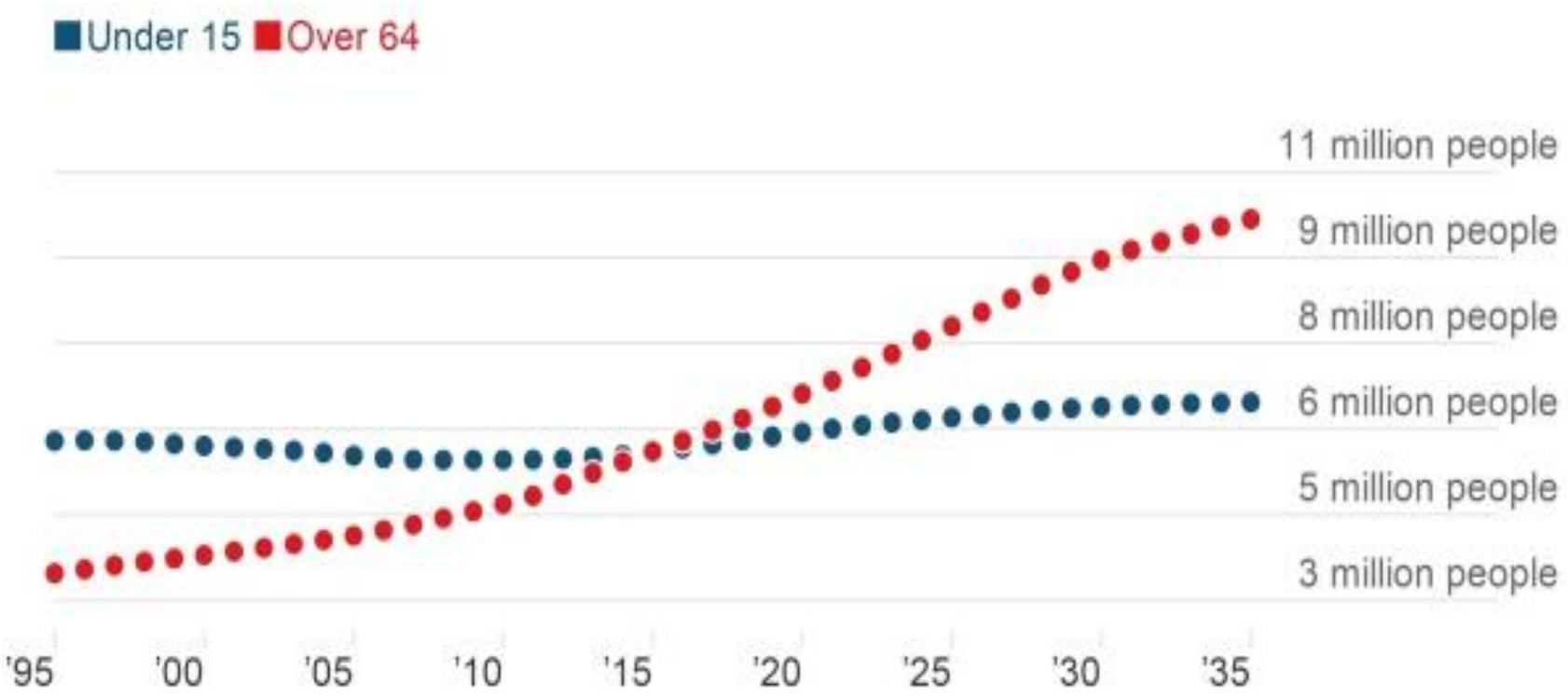
Facts about Aging

- More people are living longer
- Old age defined by an arbitrary chronological age





Canada now has more seniors than kids under 15

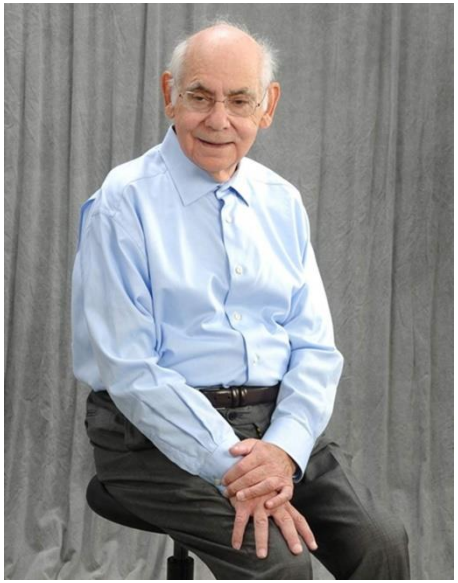


Facts about Aging & ID

- Mild to moderate ID life expectancy is similar to the general population
- First generation to outlive their parents in significant numbers
- Misperception that all people with ID age prematurely
- Nature of supports and services required to support successful aging in this population is in its early stages

Contributing Factors

Steven Reiss



- Diagnostic Overshadowing

- Misattribution of symptoms to the persons' intellectual disability
- the tendency to wrongly attribute all symptoms and signs to the disability, leading to the extension of the disability into other areas

- Dismissing needs on the basis of the intellectual disability

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HOW CAN AGENCIES PLAN & PREPARE?

- Orient staff who work with middle-age and aging adults to pick up on **cues** for dementia onset
- Train staff in techniques of providing 'dementia-capable' supports
- Review expenses and budget for adjustments as health and function affect variations in costs
- Adapt housing to incorporate measures for dementia supports / care

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HOW CAN AGENCIES PLAN & PREPARE?

- Review support / care settings to examine how they adjust to stage-based progression – particularly as adults move to advanced dementia
- Establish clinical supports / consultation to staff working with adults with dementia
- Connect with diagnostic resources for early screening, assessment, and diagnostic tracking

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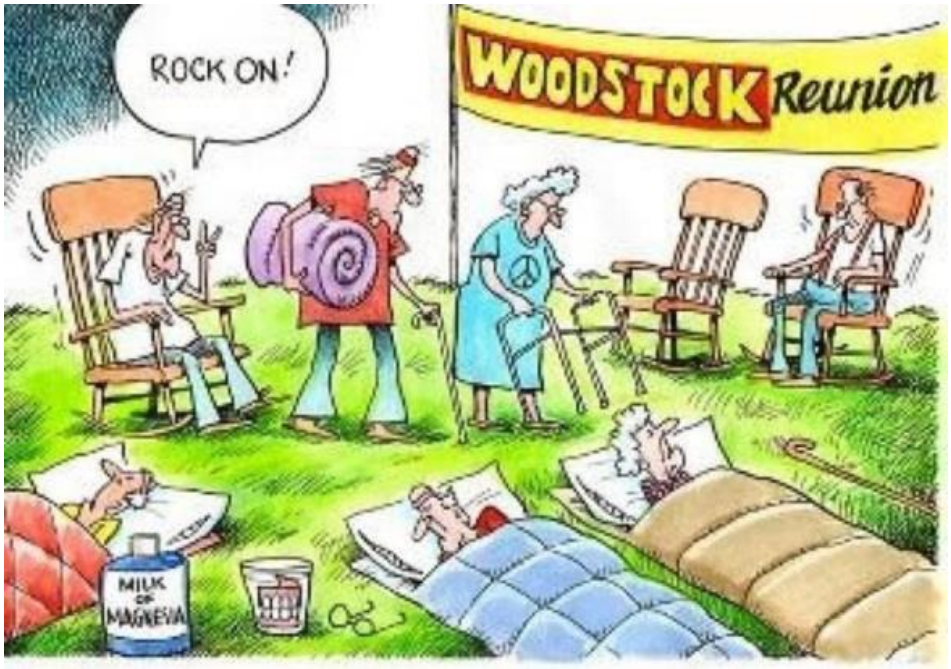
INTERVENTION/SUPPORTS

- successful aging has three components:
  - absence of disease and disability;
  - high cognitive and physical capacity;
  - active engagement with life, including productive capacity and interpersonal relationships



The Vision of Healthy Aging

Guiding Principles

- Dignity
- Independence
- Participation
- Fairness
- Security

Selected Areas of Focus

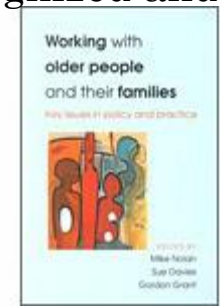
- Social Connectedness
- Physical Activity
- Healthy Eating
- Falls Prevention
- Tobacco Control

These five focus areas and principles are the first to be addressed.
Other areas (e.g., elder abuse, income disparities, literacy and lifelong learning) may be addressed later or in other collaborative strategies in advancing healthy aging.

Intervention/Supports

Mike Nolan

- From the perspective of "senses"
  - *A sense of security*:
    - freedom from pain or discomfort and attention to physical and psychological needs
  - *A sense of continuity*:
    - recognition of an individual's biography and connection to their past
  - *A sense of belonging*:
    - opportunity to maintain or develop meaningful relationships with family and friends and to be part of a chosen community or group
  - *A sense of purpose*:
    - opportunity to engage in purposeful activity, identify and pursue goals and exercise choice
  - *A sense of achievement*:
    - opportunity to meet meaningful goals and make a recognized and valued contribution
  - *A sense of significance*:
    - recognition and value as a person of worth



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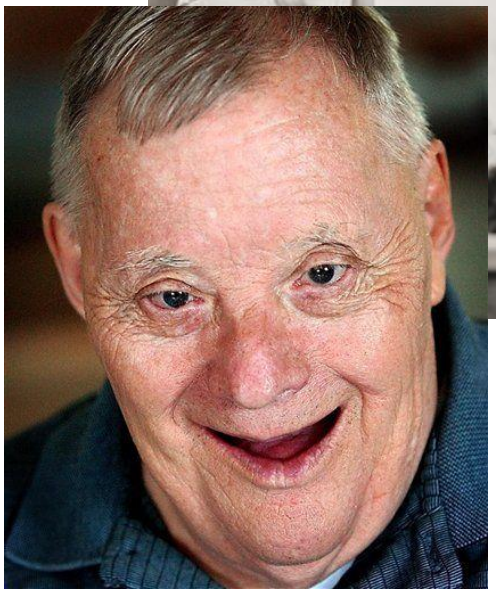

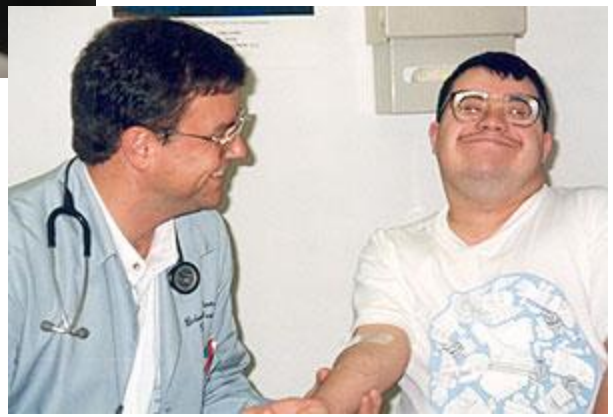

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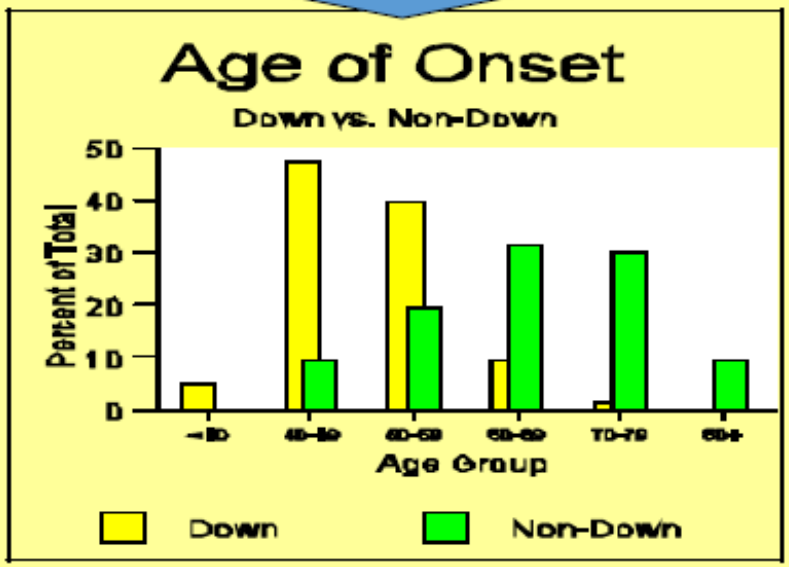
When does onset Occur?

Onset is speculative . . .

- the best we can do is identify that point when significant change or impairment has become noticeable
- in some people noticeable changes have been proceeded by MCI – "mild cognitive impairment"
- early 50s for DS – late 60s for ID

Note difference between DS (yellow) and other ID (green)



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Caution Signs/cues

- Difficulties doing familiar tasks
- Disorientation to time and place
- Misplacing things
- Changes in mood, behaviour, personality
- Memory or language difficulties

Caution Signs/cues

- Changes in routine behaviours
- Difficulty with everyday activities
- Changes in mood or affect
- Loss of initiative
- Withdraw from social activities
- Night time restlessness, seizures

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Signs & Symptoms

Early Stage	Middle Stage	Late Stage
■ Confusion and memory loss ■ Disorientation in space ■ Problems with routine tasks ■ Changes in personality and judgment	■ Difficulties with ADLs ["activities of daily living"] ■ Anxiety, paranoia, agitation and other compromising behaviors ■ Sleep difficulties ■ Difficulty recognizing familiar people	■ Loss of speech ■ Loss of appetite, weight loss ■ Loss of bladder and bowel control ■ Loss of mobility ■ Total dependence on others --- ■ Death

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Assessment

- Diagnosis of exclusion
- Early stages may be missed because of pre-existing impairments
- Difficulty obtaining history
  - Caregiver informed, multiple services
- Behaviour may mask medical concerns
- Lack of appropriate diagnostic test

Exclusions

- Thyroid Dysfunction
- Mental Illness – depression
- Sensory Impairments – hearing, vision, pain
- Infection
- Sleep apnea,
- lack of Vit B12
- Others? Consult with physician

TOOLS Ψ USES

- Concerns raised
  - Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)

- Across multiple environments/informants

- Confusion and memory loss
  - Dementia Screen for Down Syndrome (DSDS)
- Problems with routine tasks
  - Vineland Adaptive Behavior Scale
- Changes in personality
  - Reiss Profile of Fundamental Needs
  - Aberrant Behavior Checklist

TOOLS Ψ USES

- Exclusions
  - Dementia Screen for Down Syndrome (DSDS)

- Disturbances of sleep
  - Day Night Sleep charting
- Seizures
  - Seizure records
- Observations
  - Across settings

Early Stages Care

- Maintain routine and environment
- Ensure safety considerations
- Simplify/modify tasks where indicated to enable independence and self esteem
- Optimize the individual's sense of success

Middle Stage Care

- Adapt communication skills to person's level of understanding and acknowledge what they say
- Modify activities of daily living to provide support while enabling independence
- Monitor for possible pain
- Ensure safety
- Provide Care-giver support

Late Stage Care

- Meet the need for constant support and supervision
- Ensure nutritional needs are met
- Attend to personal care, skin integrity, pain
- Plan for end of life
- Special consideration to care giver support

Supporting Aging Individuals

- Early screening
- Utilize clinical supports
- Modify environment
- Programme Adaptations
- Specialised Care

In Conclusion

There is an inherent problem of growing older in systems that have not accommodated older people previously (Janicki, 1999).

Case Study # 1

Janice Elms, M.A., C. Psych. Associate

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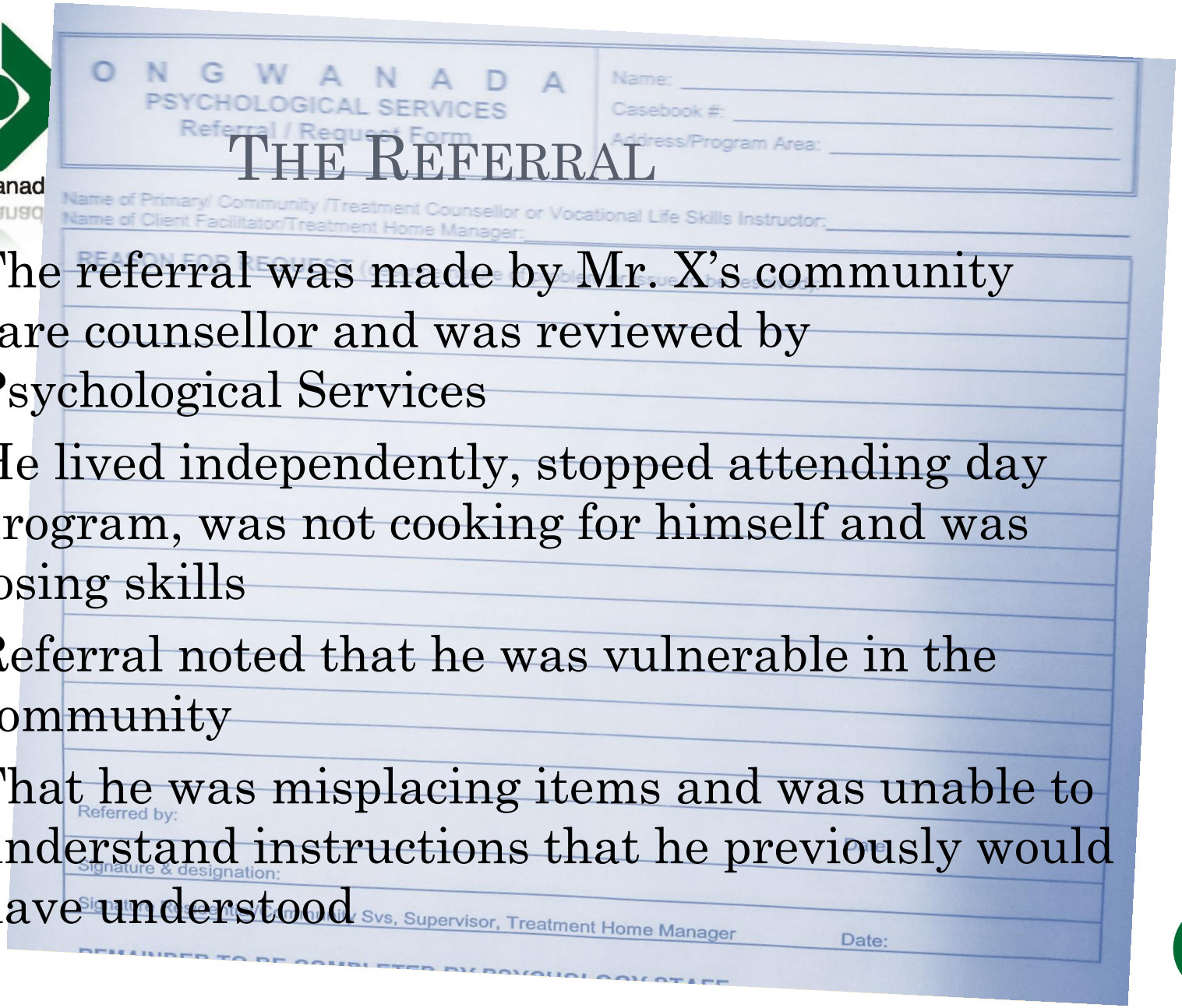
The Referral



- The referral was made by Mr. X's community care counsellor and was reviewed by Psychological Services
- He lived independently, stopped attending day program, was not cooking for himself and was losing skills
- Referral noted that he was vulnerable in the community
- That he was misplacing items and was unable to understand instructions that he previously would have understood

The Referral

- The request was for an assessment of a possible dementia
- There had not been any previous dementia assessments
- He was deemed in high need

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Background

- Mr. X is a 63 year old man
- Lives alone in a large apartment building.
- He is very social and often socially inappropriate.
  - He may comment in a loud voice about people appearances or discuss things of an intimate nature with strangers
- Individual was on medication for *bowel care*, *calcium* and *acid reflux*.

Assessment

- Baseline dementia assessment completed
  - can be used to measure future assessments against
- Personality assessments
- Adaptive living skills assessment (day to day functioning)
- Clinical records review
- Interviews with staff

Assessment

- *Dementia Scale for Down Syndrome* (DSDS)
- *Vineland Adaptive Behavior Scales*, 3rd Edition, Comprehensive Interview Form(Vineland 3)
- *Aberrant Behaviour Checklist*
- *Reiss Profile of Fundamental Goals and Motivation Sensitivities for Persons with Mental Retardation*
- *Reiss Screen for Maladaptive Behaviour*

Historical Information

- Has a moderate level of intellectual disability
- Suspended regularly from school from a young age
- Forensic history of minor assaults and theft
- Had convictions in the past for public intoxication and petty theft.

Mild

- 85% of ID Population
- Can generally learn reading, writing, and math skills between third- and sixth-grade levels. May have jobs and live independently.

Moderate

- 10% of ID Population
- May be able to learn some basic reading and writing. Able to learn functional skills such as safety and self-help. Require some type of oversight/supervision.

Severe

- 5% of ID Population
- Probably not able to read or write, although they may learn self-help skills and routines. Require supervision in their daily activities and living environment.

Profound

- 1% of ID Population
- Require intensive support. May be able to communicate by verbal or other means. May have medical conditions that require ongoing nursing and therapy.

Results

- No dual diagnosis indicated
- Overall level of adaptive function is below the 1st percentile.
- Communication and daily living skills are both below the 1st percentile. Socialisation (functioning in social situations) is a relative strength.
- No symptoms regarding the possibility of a dementia process.

CAUTION SIGNS/CUES

- **Difficulties doing familiar tasks**
- **Disorientation to time and place**
- **Misplacing things**
- Changes in mood, behaviour, personality
- Memory, Language difficulties
- **Changes in routine behaviours**
- **Difficulty with everyday tasks**
- Changes in mood or affect
- **Loss of initiative**
- **Withdraw from social activities**
- Night time restlessness, seizures

Assessment Results-stove

- Landlord got a new stove for him and everyone in the whole building
- Went from a basic stove to and digital electronic one.
- Counsellor arranged for meals from a local delivery service but this is expensive and takes up a large part of his budget. It is not a long term solution.

Assessment Results-possessions

- Through interview it was discovered that he was not misplacing his possessions. They were likely being stolen. There are a number of unsavory people who visit during the week and it has been found that they are taking his items.

Assessment Results-Day Program

- Primary counsellor at Day Program retired so Mr. X thought that he should too
- In addition his favourite work placement was discontinued so he felt that there was no need for him to come

Assessment Results

- Due to his limited cognitive abilities he is likely functioning at his maximum capacity and has developed very good socialisation skills to compensate for other life skills that he does have the ability to possess. As he ages he will become less able to get by with his 'street smarts'.
- Looking at moving him to a seniors home when he turns 65 but they have time to work on some of his less socially acceptable mannerisms

Assessment Results

- Police and landlord call counsellor if they have concerns

- Landlord replaced stove with simpler model

Recommendations

- To be referred again if there were future concerns of dementia
- Physical health concerns would need to be ruled out first
- Depression, thyroid, hearing, vision, medication interactions

Conclusions

- Appropriate referral
- Report for future needs
- Recommendations for future

Case Study # 2

Lori Burt, Dp. BST, Behaviour Therapist

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Introduction

- 59 year old man living with his family (Sibling)
  - After his parents passed away

- Since then, he had several other significant losses
  - an aunt, uncle, mother-in-law (sibling's), cousin and a very close friend

Introduction

- Diagnosed with chronic renal disease and started dialysis treatment (4hrs – 3 days/week)
- Decreased acceptance in attending dialysis treatment started shortly after his close friend died
- He and his sibling's family moved into a new home

CBS Referral

Reason for referral:

Challenging behaviour around medical appointments

Challenging Behaviour:

Refusal, crying, repetitive speech, and verbal outbursts

Physical Health Issues

- Chronic Renal disease
- Low vision/cataracts
- Hearing loss
- Heart (fluid around the heart)
- Sleep Apnea
- Hypothyroidism
- Osteoporosis
- Gout
- Knee bone chip
- Torn rotary cup (physiotherapy)
- Chronic constipation
  - Hemorrhoids
- Brain tumor/lesion (CAT)
- Back fractures (falls)

Mental Health Issues

- Intellectual Disability
- Down syndrome

Factors impacting Assessment

- Recent changes in environment and routines
- Bereavement
- Physical Health issues (pain queried)

Factors Impacting Assessment

- Concerns regarding age and presence of Down Syndrome – possibly Dementia impacting behaviour
  - Several *caution signs* present
  - Several physical health symptoms *(Exclusions)* can be mistaken as symptoms of Dementia

Exclusions

- Thyroid Dysfunction
- Sensory Impairments: hearing, vision, pain
- Sleep apnea
- Environmental changes

Functional Assessment

Functional analysis, psychometrics and observation

- Informant interviews
- Direct Observations
- Antecedent Behaviour Consequence (ABC) data record
- Sleep/bowel monitoring
- Behavioural Discomfort Indicator (BDI) chart

Functional Assessment Results

- Behaviour is *most likely* to occur the evening prior to and the day of medical appointments
- Across caregivers
- Increased on days where other social and leisure activities were to occur
- The duration of time it took to complete morning routine ranged from 2-3 hours

Functional Assessment Results

- **Sleep disturbance** occurred for multiple reasons:
  - Bowel issues (diarrhea, hemorrhoids)
  - Back pain (identified back fractures)
  - Sleep Apnea (CPAP machine needed adjustments)

Functional Assessment Results

- **Bowel monitoring** identified chronic diarrhea
- **Routines** were *not* consistent at medical appointments
- **Hearing loss** *was* impacting his receptive communication
- **Physical pain** *was* contributing to some of his behaviour

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CAUTION SIGNS/CUES

- **Difficulties doing familiar tasks**
- Disorientation to time and place
- **Misplacing things**
- **Changes in mood, behaviour, personality**
- **Memory, Language difficulties**
- **Changes in routine behaviours**
- **Difficulty with everyday activities**
- **Changes in mood or affect**
- **Loss of initiative**
- **Withdraw from social activities**
- **Night time restlessness, seizures**

Dementia Assessment Results

Baseline Dementia Assessment

- Referral to Psychological Services
- Psychometrics collected
- *Dementia Scale for Down Syndrome* (DSDS), *Vineland Adaptive Behaviour Scales* (VABS), *Aberrant Behaviour Checklist*, *Reiss Profile of Fundamental Goals and Motivation Sensitivities for Persons with Mental Retardation* (RMP-ID)

Dementia Assessment Results

- **Dementia Assessment results:**

  - Regression in skills are characteristic of the early stages of a dementia process

  - A combination of exclusions may be contributing to these changes

  - The presence of Dementia is a possible contributing factor to the regression in skills given his diagnosis of Down Syndrome and a positive family history for Dementia

Intervention

- **Development of Behavioural Supports**
  - Preventative strategies
  - Challenging Behaviour
  - Education
- **Other considerations**
  - Follow-up/referral to specialists regarding physical/medical related issues
  - Referral to *ongoing* clinical service
  - Consideration of respite and long term care options
  - Additional support for sibling

Case Study #3

Dr. Sean Kerry, Ph.D., C. Psych.

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Introduction

- 50 year old male with Down Syndrome in group living environment for persons with intellectual disabilities
- Lived with his biological parents his entire life. It was after the passing of his father that he moved into a group living environment.
- Community Behaviour Services referral was initiated due to:
  - Physical Aggression
  - Secondary to aggression: inappropriate "Raspberry"noises

Points of Assessment - CBS

- Functional analysis, psychometrics and observation

  - ***Motivational Assessment Scale***
  - ***Aberrant Behavior Checklist - Community***
  - ***Behavioural Discomfort Indicators (BDI) Chart***
  - ***Sleep/Night time data collection***
  - ***Setting Events-Antecedent-Behaviour-Consequence charts***
  - ***Direct Observations***

Referral to Psychological Services

CAUTION SIGNS/CUES

- **Difficulties doing familiar tasks**
- **Disorientation to time and place**
- Misplacing things
- **Changes in mood, behaviour, personality**
- **Memory, Language difficulties**
- **Changes in routine behaviours**
- **Difficulty with everyday activities**
- **Changes in mood or affect**
- Loss of initiative
- **Withdraw from social activities**
- **Night time restlessness, seizures**

Points of Assessment

- Psychological Services Dementia Assessment
  - File Review and collaboration with Behaviour Therapist
  - Psychometrics collected using informants (family as well as a community support worker).
    - Important to use care providers who have known the individual for a long time, as they can answer questions differentiating "old" and "new" behaviours.
  - *Dementia Scale for Down Syndrome* (DSDS), *Vineland Adaptive Behaviour Scales* (VABS), *Aberrant Behaviour Checklist*, *Reiss Profile of Human Needs*

Factors Impacting Assessment

- Physical Health Concerns: Heart Murmur; Type II Diabetes (Insulin Dependent); Pins in both hips (from auto accident); GERD; Hypothyroidism; Elevated Cholesterol; Occasional onset insomnia; Bilateral hearing loss
- Mental Health Concerns: Intellectual Disability, Down Syndrome
- Previous OT Assessment Results – suggested that some of the individual's behaviours could serve self-stimulatory and/or self-regulatory functions.
  - The individual may seek out different sensory inputs.

Factors Impacting Assessment

- Bereavement as contributing factor
- Adjustment to a new environment where attention is now divided, rather than exclusive
- Pain queried. Individual has a history of "crumbling his fingers" when he is in distress, and observers have noted that this can precede challenging behaviour.
- Concerns regarding his current age and diagnosis of Down Syndrome – higher risk for dementia

Communication of Results

- Debriefing within a team setting
  - Dementia assessment suggested that the individual likely has difficulty communicating his needs (ie., need for attention, for learning, for order, etc.) and that he may benefit from additional supports.
  - Aberrant Behaviour Checklists suggested that he is likely to disturb others (intentionally or unintentionally) through his behaviour. He may engage in repetitive patterns of behaviour and may be difficult to redirect during times of agitation.
  - DSDS did not suggest any features characteristic of early stages of dementia or neurocognitive decline.

Next Steps

- Medical follow up
  - Hearing testing revealed that new hearing aids were required
  - Investigate possible prostate issues that could be contributing to night time waking and need to void
- Make minor changes in current daily programming.
  - It was identified that the individual may be “over programmed”, that too much of his day was busy.
  - Add time to relax in evenings as fatigue was found to be correlated with challenging behaviours.

Supports

- Proactive Strategies
  - Development of an individualized communication program (visually based), and generalize supports across settings
  - Monitor any physiological or medical conditions that could exacerbate the occurrence of challenging behaviours.
    - Adjust expectations and demands when coping abilities may be reduced.
  - Unanticipated change impacting challenging behaviour:
    - Prepare ahead of time for any changes that may be occurring.
    - Present the information visually (daily schedule board) and using clear and concrete language.
    - Avoid the use of abstract concepts or verb tenses (e.g., maybe, later…).
    - Reflect changes on a visual calendar and promote flexibility, i.e., *"Instead of _____, you can _____ or _____. You choose!"*

SUPPORTS

- Keys to response: Provide structure & predictability, reduce complex verbal instructions during distress, model expected responses, avoid power struggles

- Work through the behaviour by "ignoring the behaviour and attending to the person"

- Encourage him to gain control using coping/relaxation strategies ("It's time to take a deep breath. Smell the flower and blow out the candle")

Conclusion

- Closing file and follow up
- Social engagement in the residential home and community improved
- Recommendations related to future indicators (if symptoms of dementia emerge)
  - Staff should record if he becomes more confused in his daily routines, seems to forget familiar steps or processes, or if significant changes in his behaviour emerge.