Today’s lecture will cover

Part 1. Profile of disability in Australia
Part 3. Issues, obstacles and rewards in providing dietetic services for people with an intellectual disability

Part 1. Profile of disability in Australia

WHO definition of disability…
A loss of functional ability which results from impairment.
E.g. the loss of an ability to walk in a person with spinal injury is a disability.
Or the loss of speech from a stroke.

Profile of disability in Australia

Based on a 2003 ABS survey of disability in Australia…
In 2003 there were 3.9 million people (20% of the population) in Australia whose lives were affected by an impairment, activity limitation or participation restriction in the environment in which they lived.


Profile of disability in Australia

In 2003, 1,238,600 people, 6.3% of the population, were reported as having a severe or profound core activity restriction, meaning that they sometimes or always need personal assistance or supervision with a core activity (self-care, mobility or verbal communication).
Broad categories of disability include:
- intellectual/learning
- psychiatric
- sensory/speech
- physical/diverse (includes acquired brain injury)

Estimate based on all disabling conditions (people with multiple conditions counted more than once)

<table>
<thead>
<tr>
<th>Category</th>
<th>% of total population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual/learning</td>
<td>3%</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>5.2%</td>
</tr>
<tr>
<td>Sensory/speech</td>
<td>7.6%</td>
</tr>
<tr>
<td>Acquired brain injury</td>
<td>2.2%</td>
</tr>
<tr>
<td>Physical/diverse (includes</td>
<td>17%</td>
</tr>
<tr>
<td>acquired brain injury)</td>
<td></td>
</tr>
</tbody>
</table>

Profile - people with an intellectual disability (ID)

Approx. 588,000 people in Aust (3%) have an ID

About 1/3 of these have a severe or profound activity limitations (i.e. needing personal assistance or supervision sometimes or always)

Profile – terms used by disability services

“Developmental disability” - differences in neurologically-based functions that have their onset before birth or during childhood, and are associated with significant long-term difficulties

“Intellectual disability” - includes all of the following: onset before the age of 18 years; IQ below 70; deficits in adaptive functioning

(Note: ID only about 1% of the population using this definition)

Services accessed by frail aged and people with a disability

Hospitals and Community Health services
Nursing homes and hostels
Support services for people in the community……
  • Home and Community Care Services** (HACC)
  • Disability Services Program**
  • Aged Care Packages* (CACP)
  • Extended Aged Care at Home packages* (EACH)
*Commonwealth funded    ** shared Com-State funded

Disability services

including accommodation support, community support, respite, employment and community access.

Service users in 2003-4
187,806 consumers in Australia of CSDA-funded services (about 1/3 at any one time)
38% have an ID as their primary disability

CSDA* Commonwealth State Disability Agreement

Profile - Aetiology of ID

50% genetic
20% environmental
30% unknown, suspected mainly genetic

Intellectual disability

Common types of ID include:
  • Down syndrome (trisomy 21) ~ 1 in 660 live births
  • Cerebral palsy ~ 2 in 1000 live births
  • Autism spectrum disorders (include autistic disorder, Asperger’s disorder, Rett syndrome, etc)
  • Prader-Willi syndrome
  • Fragile X syndrome
  • etc..

From “5 A Day Eat More Fruit and Vegetables” booklet (Dept of Health UK 2005)
Background history

1983 - review of Mental Health Act
- no longer required declaration of mental illness for admission to an institution
1983 - Richmond Report
- separation of services
- creation of community teams and new forms of accommodation
1989 - residential care of people with ID moved from NSW Health to DoCS (and currently DADHC)

Disability services

In NSW the majority of disability (CSDA-funded) services are provided by Non Gov Orgs

However, the Community Resource /Support Teams - multi-disciplinary teams ..................are government employed (DADHC)
.........without dietitians

Disability services

"supported accommodation"

- large “residential” (institutions, hostels)
- community houses (group homes)
- respite care (centre-based or other flexible forms)

Disability services

people in supported accommodation NSW
Government-funded (ie. CSDA-funded)

- 1700 in large residences* (NGO/G = 1/2)
- 3500 in group homes* (NGO/G = 65/35)
- 1000 in other forms, mainly in-home
- 300 in centre-based respite
Plus 855 in licensed boarding houses*(private, ie. unfunded by DSP)

2006 data

Profile - health issues
• Life expectancy 20 years less than others
• Poorer levels of physical fitness
• Multiple complex disorders
• twice the risk of hospitalisation
• problems with mobility (5%) and continence (10%)
• polypharmacy
• Do not complain

Profile --nutrition & related issues
• Underweight, overweight & obesity more common
• Failure to thrive/grow
• Constipation
• Dysphagia
• Reflux oesophagitis, GORD, H. pylori
• Malnutrition
• Osteoporosis, vit D deficiency

Causes of death
Most common causes of death are:
• respiratory disease (pneumonia, inhalation, choking)
• cancer
• accidents and injuries
• heart disease (congenital)
• seizures

Percentage of deaths from respiratory disease

Ensuring Good Nutrition Policy in NSW
• launched 2003
• 6 months roll out of training
• 2 year support process through regional support committees
• monitoring framework and tools to assess compliance

Source: Community Services Commission, NSW. 2001
What is the scope of the policy?

- overarching policy
- applies to CSDA-funded accommodation and centre-based respite in NSW
- will inform other types of services
- nutrition plans expected to be communicated between services

Resources for training

- policy and appendix (2003)
- *Food Services Manual* (developed 1999-2000)
- a nutrition information kit (2003)—Informed Decision Making Pathway, nutrition information sheets

Responsibilities of the services

- Nutrition risk assessments at least annually
- Individual nutrition plans
  - Good practice means tube fed clients reviewed by a dietitian at least 6 monthly
  - Use the “informed decision making pathway” if tube feeding is considered
  - Dietitian’s assessment when a person’s healthy weight range can’t be determined because their height can’t be measured
  - Access to health professionals as needed
  - provide DADHC with evidence of how their services are achieving the objectives of the EGN policy

What does the policy say about involving dietitians?

- review tube feeds at least 6 monthly
  - if height can’t be measured
  - facilitate the involvement of a dietitian or appropriate health care professional as needed
  - use the Informed Decision Making Pathway when tube feeding is considered

Part 3. Issues, obstacles and rewards in providing dietetic services to people with an intellectual disability

Use of the Nutrition and swallowing Checklist

- Ask for the most recent checklist results if the client lives in a group home
- Use the results to discuss with the client and family or care staff
- Client should be accompanied by the “key worker” or family member
- Be prepared for further information gathering and follow up.
Issues in delivering a dietetic service

- Communication difficulties
- Accessing/obtaining sufficient accurate information
- Assessment process can be lengthy
- Negative attitudes & expectations
- Lack of appropriate education resources
- Lack of appropriate equipment for assessment (scales, skin fold calipers, etc)
- Lack of flexibility to follow-up

Wheelchair ramp over bathroom scales by Paraquad Engineering

Exercise in estimating height

19 year old woman with Cerebral Palsy. She is quadriplegic and has hip dislocations.
- Knee height 40.3cm
- Body length (segmental) left side 124.5cm and right side 127cm
- Weight 30.8kg
Calculate estimated height and ideal body weight.

When providing a dietetic service

- be inclusive in an interview/discussion
- identify the person’s support systems
- find out about the person’s routines
- ask for the latest Nutrition and Swallowing Checklist results
- ask for copies of medical and allied health reports
- simplify interventions and identify how they will be carried out and by whom

- be concrete
- negotiate short term goals
- identify practical ways of monitoring progress
- ALWAYS write a report
- communicate with other professionals
- use the eating and drinking plan format in the N in P Manual
- negotiate the review date and process