What is Old is New Again & the Challenge for the Future: Can we do it again in the context of the NDIS.

25 +++ Years (*40 years of significant change*)

The contribution of disability & psychiatric nurses to the social policy revolution era now coming to an end.

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Issues & Questions

Disability Nurses historical involvement in the move to:-

• individual person centred planning in the 1970s & 1980s,

• nurses as living skills educators,

•Nurse Program Officers as behaviour therapists

• community living (individual drop-in support, hostels, group homes)

The forgotten foundations of today's services.

An eye witness account – an active participant

Can we reinvent ourselves for the future under the NDIS?

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History prior to 1970

Historical background

- Institutional care – concentration of expertise and social control
- Lunacy Act 1878 for “the insane” & “imbeciles”
- 1st institutions on the river – Callum Park, Gladesville, Rydalmere, P’matta
- Over-crowded 1,000 pts (capacity 800) (Rydalmere) Stockton = more
- Staff under trained – employed by the pound
- Royal Commission (1st -1923) into Callum Park (2nd - 1961)
- Under staffed – large client to staff ratios (80 - 120 to 5 staff in late 60’s)

- Less than 20% of people with disability in institutions (at the peak)
- Most people with disability lived with their families
- No family support until Whitlam era (created community health)
- No community alternatives
- Even NGOs were large hostels or special purpose nursing homes

FRUSTRATION & DISATIFICATION as GREAT MOTIVATORS for CHANGE

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Genesis of Change

Staff Training – Nurse Training Schools & Staff Development agents for change

- Late 60's – Higher standards of entry (HSC or equivalent)
- 600 hours curriculum (60s) -> 800 hrs –> 1,000 hours (late 70s)
  - Nurses learning special education teaching techniques, physiotherapy, social & behavioural science, case management, program approaches
- Post-Graduate Nursing Certificate (Management)
  - Supervision, leadership, management, ward administration, organisation
- Double (Triple) Certificate Nurses & Part-time Uni (Adm / Teach)
- 1970s Training (Program) Officers Post-Grad Certificate (CNC)
  - University lecturers and researchers from Macquarie Uni, Sydney Uni, NSW Uni, Newcastle Uni,
  - Assessment – skills of daily living, behaviour analysis, vocational skills
  - Program development – Special Education Instructional methods
  - Advanced behavioural science – behaviour change programs
  - Assignments – real people, real needs, real challenges for real outcomes

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Separation of Services

- **Late 1960s Allan Jennings Report – creation of specialist disability services**
  - **Assessment Diagnostic Team, Peat Island, Milson Island, Stockton, Grosvenor, Collaroy Annex, Marsden, AGSSOMD (ASID)**
  - **New wards – smaller populations (80 -> 35) (1961 Royal Commission gradual and slow roll out)**
- **Early 1970s Gradual Separation Of Disability from Mental Health Services**
  - **Gender integration – staff and clients**
  - **Handicapped Persons Services**
  - **Nurses & Psychologists leadership (Doctors in some places)**
  - **New day program units**
  - **Specialization program units**
  - **Enhanced recreation programs**
  - **Allied health professionals (when we could get them)**

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Individual needs

Early 1970s Assessment of Individual needs

- AAMD Adaptive Behaviour Scale/ Gunsberg Social Maturity Scale
- Living Skills Inventories (community referenced)
- AAMD Abberant Behaviour Scale (locally refined)
- Behaviour Baseline data collection (client focused)
- Multi-disciplinary assessments
- Individual Management Plans ->Individual Service Plans
- Case Conference including Family & clients (their hopes for the future)
- Long & Medium Term Goals
- Program grouping according to needs & functional levels
- Individual Program Plans, Individual Behaviour Plans
- Skill Instruction Plans

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Individual Clients Rebelled

- **Early 1970s – Some Individual clients rebelled**
  - Clients who discharged themselves (officially - absconded)
  - Didn't like the institution – didn't want to come back
  - First female client
  - Out reach support (August 1973)
  - Help get pension redirected – Bank account opened - Help budget and shopping skills - Weekly support meetings
  - Help them find accommodation & Link with local doctor
  - Help find a job – (industrial area of Rydalmere)
  - Get into Parramatta Evening college course (cooking)
  - ACROD (now NDS) – Disability Education Committee – lobby TAFE and Community Colleges for more education programs for people with a disability.
  - ACROD – Recreation Committee – lobby Sport & Rec for more disability programs
  - (Both Chaired by Rydalmere Nurses)

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New Community Team

- **Community Team (early 1970s)**
  - Two community nurses – Western Metro Region adolescents & adults (Social worker did nursing home follow-ups)
  - Support for discharged clients
  - Family liaison and support
  - Day program day only attendance (mostly workshop)
  - Temporary (Respite) care – discharge agreements
  - Admission only if necessary
  - Alternatives to admission – scarce
  - Community Living Skills Program – Parent Education Program
  - Community work placements – Sheltered Workshops & open employment in industrial area

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First Group Home 73-74

Need for alternate accommodation options

- For those capable of semi-independent living
- Program Director Lloyd Gathman …
- liaison with Guildford Rotary raised funds to furnish houses and flats
- House rented from Rotarian who owned Cake Shop in Merrylands
- Community Nurse liaised with families & arranged social security matters
- Deputy Charge Nurse W16 – seconded as First live-in house parents
- Program Officer (me) – Living Skills Program Plans & Priorities
- Flat at North Parramatta – two young men – as an alternative to admission
- Charge Nurses suggesting future clients, preparation programs (W21, W25)
- Preparation Cottage - on grounds – for future preparation
- House at Collett Park (offered by Nurse)
- NO FUNDING, NO POLICIES – just initiative

Health Commission of NSW & After Care Association Working Party

Guidelines for Establishing Half-way Houses and Community Living

- No group homes, hostels to use an example.

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Concept Spreading

- **Community Living Concept Spreading**
  - Gladesville auxilliary set up by nurses – renting houses in Gladesville
  - Marsden Rehabilitation Centre – Hostel in Hawkesbury Rd Westmead
  - Hostels, Boarding Houses and Half-way Houses popping up around large Residential Centres in the state – started by nurses
  - Hornsby Hospital – bequeathed estate houses
  - By late 1970's Rydalmere had 10 flats and houses in the community
  - Rydalmere Community Team as drop-in support
  - 24/7 On Call Roster – Crisis On Call – beepers purchased from petty cash
- **AAISH (Association for the Assistance of the Socially & Intellectually Handicapped) – now Ability Options.**
  - Early 1970s an informal committee with Rydalmere staff & Guildford Rotary Club with Lloyd Gathman
  - Then as an unincorporated Association with Chairman (Norm White from Guildford Rotary), May Quarm Treasurer (Secretary of Rydalmere Handicapped Persons Service) later Carol Borg
  - Greg McIntyre (1977 Program Director) Incorporated in late 1970

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Health Admin Changes

Other Contextual issues – Health Administration

- Comprehensive Health Systems – from home to hospital and back.
- Community health linkages with hospitals
- Coordinated care concepts – Prevention emphasis – Family support emphasis
- Link with other government & community agencies – Local Government, Schools, FACS, Children's Services, Aged Care Services, Housing, Welfare, NGOs.
- Commonwealth funding to community services (NGOs) increasing

Other Contextual issues – Mental health

- Community health linkages with hospitals
- Creating mental health units in Public Hospital system – more distributed to population
- Less stigmatising for clients and family
- Pilot Community Crisis Teams & Prolonged Follow-up Teams
- Pilot Mental health Living Skills Programs
- Research in taking referral patterns away from Psychiatric Hospitals

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The times are a changing

Other Contextual issues – Vocational & Professional Education

- 1970s shift towards professionalization – credential pre-requisites
- Government departments shifting staff training to TAFE colleges
- Government departments employing more university graduates
- Grade 5 and above (a graduate level)
- Government departments advise universities of needs
- Government department bonded scholarships (out of 60s skill shortages)
- Government Post-Graduate Programs to University Post-graduate programs.

- Transfer of professional colleges to universities
- (Occupational therapy, Physiotherapy, Radiology, Diversional Therapy, Youth Work)

- Transfer of Nurse Education to Universities (world-wide trend)
- Transfer of other staff development to TAFE or universities
- Any future staff training needs and plans to involved TAFE and universities
- Not to commit to internal obligations (Richmond Report to come)

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1980s Richmond Inquiry

❖ Richmond Inquiry & Richmond Report

- ❖ Public meetings, private submissions, many nurses in the system recommending alternate systems for people with a disability and for the mentally ill in the community – **David saw what Rydalmere, Marsden, Hornsby & Gladesville had established.**
- ❖ Richmond Review & Evaluation Steering Committee Unit (RESCU) 25 May 1984
- ❖ Two Registered Nurses in the state-wide coordination unit
- ❖ Richmond Implementation Unit (1984)

❖ Review & Evaluation Phase Issues

- ❖ Lack of community support systems in many areas of the state
- ❖ Most people with disability lived with families in the community
- ❖ Create or expand community teams where they previous had not been
- ❖ Existing Services not distributed according to shift in population
- ❖ Many families separated by large distances from family members
- ❖ Need for local accommodation options distributed according to population
- ❖ Moving clients from one structured environment to a smaller structured environment
- ❖ It will cost more – and not save money – extra state allocation needed

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Richmond Implementation

Strategic Issues

- Implement Principles of Care but not the entire Report
- More integrated into the Community Health & Regional Health administration system
- Services in same town as families – rebuild family relationships/ involvement
- Move from 50% budget funding parks & gardens – with poor client to staff ratios
- Most of budget to direct care (70-80%) with 1-2 staff to 4-5 clients
- Property costs averaging across the state
- Also Deal with Public Housing
- Mostly departmental units – a few funded NGOs
- Normal houses close to public transport and community amenities
- Greater community access, utilising community resources and amenities
- Increased opportunity for teaching skills of daily living
- Increased life enrichment

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Health Admin Changes

Other Contextual issues – Disability

- Community Disabilities linked to Community Health & Hospitals
- 22 Specialist Regional Coordinators – 11 Nurses & 8 Psychologists & 1 MD, 2 DPM
- Community Multidisciplinary Teams with Community Nurses,
- More local Assessment Services
- Core & Cluster Model - Residential Service Managers (Nurses)
- Residential Management Course (Dianna Daley – Sydney Uni)
- Program teams (Nurse Program Officers, Psychologists)
- House Managers (most Nurses)
- Residential Care Workers (salary benchmarked to Registered Nurse pay scales +)
- RCW (Registered Nurse or Associate Diploma or above eg Special Education, Psychology, Occupational Therapy, Welfare Diploma or Degree)
- Residential Care Assistants (salary benchmarked to Enrolled Nurse pay scales +)
- (attracted Enrolled Nurses and Assistants in Nursing, Certificates in Community Welfare, Youth Work, etc. – attitude and motivation pre-requisite)
- Staff training – Charles Sturt University – Associate Diploma in DD, 168 events.

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Motivation for change

Motivation during the era of change

- **Initially about specific individuals needs**
- **Nurses genuine concern for their clients welfare and future**
- **Nurses seeing individuals potential for a better life**
- Local issues – (not social policy) – about real people real needs.
- Lack of resources led to resourcefulness
- Saw other ways of doing things
- Nurses using knowledge and skills in new contexts
- Nurses taking the initiative
- Willing to make a commitment
- Just do it
- **NETWORKING – PEER SUPPORT – ASID, ACROD (NDS), PANDDA**
- Sharing knowledge – listening to others experiences
- **Later came to wider social policy implications**

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The future

The contribution of disability & psychiatric nurses to the social policy revolution era now coming to an end.

- So are we motivated and concerned by real peoples needs
- About 80% of people with disability live with the families – under supported
- Hence the widespread need for the NDIS

- So what needs do we see we can meet in the new social and organisational context of the NDIS?
- So what skills and knowledge can we contribute to meeting those real world needs?
- **Can we re-invent ourselves?** Like many of us had in the era just past.
- What will the future be?
- **Where are the opportunities for you to make a difference?**
- **"Success comes to the prepared mind" Robert Louie Stevens**

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Thank you

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Providing nurses and disability care workers

Global: for nursing and disability care staffing services