Intellectual disability: Post World War II Institutionalisation to Contemporary Deinstitutionalisation: The lived experience.

Presentation to the Australasian Intellectual Disability conference

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Presentation Outline:

1. Study objective is to examine the ‘lived experience’ of administrative frameworks of an intellectually disabled person from PWW2 to now

2. Research method is mixed qualitative and archival study anchored in chronological survey

3. Setting the scene: a case study

4. Preliminary research findings

5. Conclusion & discussion
2. Research method

- Mixed qualitative research approach
- Archival analysis
- Analysis of the lived experience in light of:
  - Administrative frameworks (legislative instruments)
  - Policies
  - Philosophical approaches (e.g., institutionalisation, medicalisation, socialisation, personalisation)
  - Administrative data
3. Setting the scene: a case study

Key findings about population characteristics:

- John Richard Gowlland ‘Ricky’
- Born 1948, Sydney.
- Born with hydrocephalus
- Lived with parents, older sister and later baby sister until 6 yrs
- Institutionalised under the Lunacy Act of 1898 – sch 4 – age 6
- Lived at Watts Street ‘psychiatric hospital’ Newcastle until age 13
- Lived at Peat Island, Hawkesbury Rv 1961 until 2009
- Lived at Causarina Grove, Wyong 2009 until 2012
Mr. and Mrs. J. Gowland, of Mosman, had a family party at their home yesterday afternoon, following the christening of their son, John Richard, at the Congregational Church, Mosman.
1946 – 1952 life at home as a baby to toddler

- Several medical procedures for hydrocephalus
- Social attitudes of the day
- No carer assistance (except a cleaner half a day once a week)
- A growing family
- Breaking point
- Options – *Lunacy Act of 1898 – 4th schedule*
LUNACY ACT OF 1898—FOURTH SCHEDULE.

I, the undersigned, hereby request you to receive (a) John Richard Gowlland a person certified to be insane into the (b) Mental Hospital (or Licensed House) of which you are the Superintendent. Subjoined is a statement respecting the said person.

Name of person signing the Request.

John Frederick Gowlland

Occupation (if any) of that person.

Salesman

Place of abode.

74 Middle Head Rd. Moosman

Degree of relationship (if any) or other circumstances of connection of the person signing the request with the person so certified to be insane.

Father

Dated this (c) 17th day of (c) August, 1952.

Signature of person making request.

Jo Gowlland

Witness to Signature (d)

Cdr. Power J.P.

To (e) Drs. W. Kirkwood,

Superintendent of the Mental Hospital,

at (f) Newcastle.

[TURN OVER]

MEDICAL CERTIFICATE TO ACCOMPANY ORDER OR REQUEST FOR RECEPTION INTO A HOSPITAL OR LICENSED HOUSE.

I, the undersigned, being a medical practitioner, hereby certify that I, on the fifteenth day of August, 1952,
at (number of house) 74 Middle Head Rd. Moosman (airis)
Sydney (town) separately from any other medical practitioner, personally examined John Richard Gowlland of (c) 74 Middle Head Rd. Moosman.

whose occupation is (e) Child.

and that the said John Richard Gowlland (insane) (b) and a proper person to be taken charge of and detained under care and treatment, and that I have formed this opinion upon the following grounds, viz.:

1) Facts indicating insanity observed by myself.

This child has been under my care since infancy. He had as an infant hydrocephalus treated by drainage of a sub-dural cyst, probably the result of birth trauma.

He has been very backward in learning to walk, talk, and control his excretory. At the present time (9 years old) he can say a few words, can feed himself imperfectly and frequently soiled his clothing with urine and feces. Present mental age about 2 years.

2) Other facts (if any) indicating insanity communicated to me by (c).

It is unsafe to leave him unattended as he has no idea of danger to be avoided and he has a strong tendency to wander from home. His parents are unable to devote proper care to their other children because of the demands caused by this one.

Dated at Moosman this fifteenth day of August, 1952.

Signature: Edward N. Astwick

Qualification: M.B. B.S. (Syd.) 1931

Place of abode: Moosman.
1950s living at Watt Street, Newcastle:

- Legislation sanctioned Ricky living at Watt St – Lunacy Act
- Living in hospital setting
- Attended preschool (one of the attractions of sending Ricky)
- Learnt to be toilet trained and feed himself?
- Correspondence from my grandparents asking to take Ricky home when sick was met with ‘best to keep him here’.
- Limited family visits - no car & distance from Sydney to Newcastle. Kind boss who lent a car.
- Puberty approaches – time to move on.
N.B.—This is an interim receipt only, in respect of money received, and an Official Receipt will be issued subsequently.

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**Newcastle Mental Hospital**

14th 12th 1957

Received the undermentioned articles from **D. Jones**
on behalf of patient **R. Goodland**

<table>
<thead>
<tr>
<th>Description of Article</th>
<th>Condition of Article</th>
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</thead>
<tbody>
<tr>
<td>1 Car Transport (Xmas present)</td>
<td></td>
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</table>

Signature **J. Goodland** — Receiving Att. or Nurse
Signature **R. Jones** — Charge Att. or Nurse

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9 Little Street,
MOSMAN.
9th May, 1961.

The Manager,
*the & Milsons Island Mental Hospital,*
HAWKESBURY RIVER.

Dear Sir,

Enclosed please find cheque for £1/-/–, being pocket money for my Son, John.

Thanking you,

Yours faithfully,

[Signature]

J. Goodland.

Encls:

[Stamp] 11 May 1960
1960s

- 1961 – move to Peat Island, Hawkesbury Rv, NSW
- Purpose of Peat & Milson Islands
- Limited administrative files from this period
- Family contact once a month or less (more often admin contact was made with family)
- Ongoing attitude of institutionalisation and medicalisation
- 1969 beginning of chronic medical problems & interventions
- Mental Health Act 1958
1st April, 1969.

Mr. J. Gowlland,
9 Little Street,
Mosman, N.S.W. 2088

Dear Mr. Gowlland,

It was discovered at routine clinical examination that John has a left inguinal hernia. He is being admitted to the Surgical Unit at North Ryde Psychiatric Centre on April 11, 1969, for operation.

If you wish further information, please telephone me or if you wish to enquire after him when he is in North Ryde Psychiatric Centre, you may do so by telephoning 880281 and asking for the Surgical Unit.

Yours faithfully,

D.G. LINDSAY
Medical Superintendent

TRANSFER OF PATIENT

SECTION 20 (2) — MENTAL HEALTH ACT, AS AMENDED

NAME OF PATIENT TRANSFERRED: GOWLAND, Richard

FROM: Pent Island Hospital
TO: North Ryde Psychiatric Centre Hospital

The abovementioned transfer in terms of Section 20 (2) of the Mental Health Act has been arranged with your concurrence to take effect from

1st December, 1975

A/ Medical Superintendent

Pent Island Hospital
1st December, 1975

To Medical Superintendent,

N.R.P.C. Hospital,
1970s:

- Peat Island lives in Seabreeze – men’s dorm
- Limited administrative data kept
- In and out of Ryde Psychiatric hospital for procedures and treatment of hernia
- Medical model dominant. No parental/guardian consent papers evident (nb it wasn’t legally required)
- Mental Health Act 1958
1980s:

- Living in Seabreeze men’s dorm at Peat Island
- Ongoing medical procedures and stays at Ryde Psychiatric Hospital for hernia
- Limited family visits (one per month), poor paper records
- Beginnings of socialisation and normalisation, e.g. more outings offered. A cafe established on Peat Island. Work.
NAME: Cowland John

DATE: 31-8-46

height: 1.56m
weight: 74 lbs.

hair: Brown
eyes: Blue
complexion: fair

features: sensory defects

language: English

Personality: likeable and helpful

likes: Outings, work

dislikes
1990s:

- Continue living in Seabreeze men’s dorm
- Hornsby Hospital for hernia – clearer documentation & consent sought.
- Limited family visits (one per month), better paper records. Activity of the parents of Peat Island.
- Files focus on ‘incident reports’ and ‘work’.
- Statute: Disability Pension (cwth), guardianship act (NSW), Disability Services Act 1993 (NSW)
Dr. C. Jones
Peat Island Centre
BROOKLYN  2083

Dear Dr. Jones,

re: Mr. John Gowland

Thank you for referring Mr. Gowland who has quite a large right inguinal hernia.

I remember him well when I saw him previously for a continuing discharge from a sinus from an upper midline surgical wound. At that stage a right inguinal hernia was noted but I felt it should be left alone, at least until his abdominal sinus had healed.

Fortunately the abdomen seems to have settled and now the hernia needs to be repaired.

I am arranging for this at Hornsby Hospital in due course.

With kind regards.

Yours sincerely,
2000 - 2012:

- Period of huge change. Philosophical shifts.
- Three moves within Peat Island and then final move to ADHC ageing disability facility Casuarina Grove, Wyong
- Five key hospitalisations (3 not for resuscitation requests)
- Period of anthropophobia & stop work.
- Renaissance of proactive family involvement.
- Deinstitutionalisation and personalisation.
- Statute: Disability Pension (cwth), guardianship act (NSW), Disability Act (NSW)
NEW SOUTH WALES
BIRTHS, DEATHS AND MARRIAGES REGISTRATION ACT 1995
DEATH CERTIFICATE

REGISTRATION NUMBER
115076/2012

1 DECEASED
Family Name: GOWLAND
Christian or Given Name(s): John Richard
Date of Death: Between 16 and 17 April 2012
Place of Death: Casuarina Grove, 110 Louisiana Road, Hamlyn Terrace
Sex and Age: Male, 65 years
Place of Birth: Casuarina Grove, 110 Louisiana Road, Hamlyn Terrace 2259
Life: 
Period of Residence in Australia: 
Place of Residence: 
Usual Occupation: 
Marital Status at Date of Death: Never Married

2 MARRIAGE(S)
Place of Marriage: 
Age when Married: 
Full Name of Spouse: 

3 CHILDREN
In order of birth: 
names and ages: 

4 PARENTS
Father’s Name: John Frederick GOWLAND
Mother’s Name: Beatrice Valmai BOOTH
Mother’s Maiden Family Name: 

5 MEDICAL
Cause of Death: (i)(a) Aspiration
and Duration of last illness: (b) Dysphagia

Name of Certifying Medical Practitioner or Coroner: D McLennan, Coroner

6 BURIAL or CREMATION
Date: 24 April 2012
Place: Mackay Family Crematorium, Ormabah

7 INFORMANT
Name: C Andrews
Address: 2/12 Esther Road, Mosman 2083
Relationship to deceased: Sister

8 REGISTERING AUTHORITY
Name: Greg Curry, Registrar
Date: 04 May 2012

9 ENDORSEMENT(S)
Not any

Before accepting copies, sight unaltered original. The original has a coloured background.

I hereby certify that this is a true copy of particulars recorded in a Register in the State of New South Wales, in the Commonwealth of Australia

REGISTRY OF BIRTHS
DEATHS AND MARRIAGES

SYDNEY
04 May 2012

Registrar
4. Preliminary research findings:

- Adverse impact of institutionalisation on the person and family involved
- Despite the rhetoric of deinstitutionalisation having occurred clients are yet to reap the full benefits
- Personalisation has not yet taken full affect
5. Conclusion and discussion:

- The lived experience of institutionalisation to deinstitutionalisation is relatively un-researched in NSW.
- Similar studies?
- How to find other case studies (issues: access, capacity, consent).
- Medical procedures and Ryde?
General Discussion

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