The José Jancar Lecture

Past and future

Peter Carpenter

This Lecture

- Joze Jancar
- Born 1920 near Ljubljana in new Yugoslavia
- Became medical student in 1942
- survived Italian death reprisals and emigrated England where worked at Northam Colony/Hospital.
- Medical Degree Ireland 1952 DPM Ireland 1955
- Joined staff Stoke Park 1956 under Alan Heaton Ward.
- Died 2000
- Large output of research.
- Champion of retaining the hospital services

My talk

- Attitudes to ID
  - Medics and others
- Isolation
  - Crises
  - Champions
- Who do we look after
  - Life after the hospitals

Attitudes -The Golden Age

- It was the institutions wot have caused our current attitudes
- Samuel Hitch reviewed poor law cases in the community in Leicester in 1844
**Stephen aged 28 - Imbecility with epilepsy**

His mother receives so much per week to take care of him, but she admits that frequently for a whole day she knows nothing about him, he wanders away not knowing where and gives her great anxiety, she fearing that he may have met with some accident. He is said to be a boy 'of good disposition' but possessing many personal peculiarities and being allowed to wander about the street the boys make fun and tease him, this irritates him and makes him violent and his mother says that she is afraid some harm will happen as his disposition is changing and he is becoming much more irritable and less easy of control. … he should be placed in some place for better security, not in a Workhouse nor a Lunatic Asylum.

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**Thomas aged 29 - Epilepsy - fatuous since age 7**

This poor epileptic has many and frequent paroxysms of fits and for his own protection requires to be secured to his seat constantly. Without such he would fall and injure himself. He lives with his mother who appears kind to him. He is harmless and susceptible of no relief.

**Ann 24 - Imbecility with epilepsy (daily paroxysms)**

a hopeless case but wants more efficient protection. She was laid hold of by some scoundrel & became pregnant and now has a fine boy with her. She wants a good guardian. At present resides with her parents who have a large family of small children.

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**Attitudes**

- In 1909 when Leicester opened its first home for a group of lads with mental deficiency (some with Down syndrome) The manager had to undertake to keep them indoors and out of sight at times children passed to go to school.

- In 1960's when MHA opened the hospitals, the Scouting movement started to restrict membership.

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**Medical Attitudes**

- Old style teaching - list the syndromes, observe the patients.
- Enabled assessment to last 5 minutes.
- Sterilise the lot of them!
- In the 1980’s changed to be about attitude change: make them talk, make them interact.
- But still most dangerous subdiscipline?
Nursing attitudes

Need to Take the staff team with you
  • Brentry Therapeutic Community 1970 - 74
  • 1970s adventure playgrounds.

Extensive attitudinal retraining at time of transfer to community.

Attitude attributes causes to behaviour

Isolation

• Bath Idiot and Imbecile Institution - subscribers asked visit and help, children walk around town every day.
• Idiot Institutions - on the hill, isolation.
• Leave your children with us, they will be looked after.
  • See your loved one in reception supervised by a nurse.
    • Hortham - beatings
    • 1970’s ill-treatment enquiries.
Isolation

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- Leave your children with us, they will be looked after.
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  - Hortham - beatings
  - HCC/CQC - visits must be off ward.
  - 2011 Winterbourne View.

We need champions but who will they be?

- Alan Heaton Ward - Stoke Park Hospital Group
  - 1972 HAS criticised Stoke Park. Student nurses leaked to press.
    - AHW: It is a slum. Invited TV in: 24 Hours - Stoke Park horror
  - 1972 new wards allowed [Funding up 30% 1965-9; 100% 1969-74]
  - Own experience as new SpR Farleigh 1986 - campaign that closure underfunded, not planned. [John Roylance CE - how dare you rock the boat!]

Crisis and Scandal

- Longcare care homes 1998
- Cornwall 2006
- Bromley PCT, Sutton and Merton PCT 2007
- Winterbourne View 2011
- Was it the fault of the PCT, SS, Safeguarding, CQC, SHA or care coordinators. Or the Provider?
  - Or of government policies?

Who do we look after

Our role was defined by

- 1913 Mental Deficiency Act
  - Idiot [incapable guarding self from common dangers]
  - Imbecile [incapable of managing themselves or their affairs]
  - Feeble minded [Incapable of instruction]
  - Moral defective [on whom punishment/treatment as little effect]
  - Act dealt with you if you fitted one of the above and
  - Neglected, mistreated or without support
  - Habitual drunkard
  - In receipt of poor relief whilst pregnant with an illegitimate child
Effect

- Majority adults in Mental Deficiency Colonies would not now be eligible for a service from us.
- Brentry: 1940's lecture by medical superintendent talks of the problems when patient more intelligent than staff.
  - Grades 1933: patient ran ward, kept minutes of meeting to show Superintendent. Nurses visited once a day.
- 1959 Mental Health Act - most of the patients discharged afterwards never seen again.

Change of a specialism

- Mental Handicap Doctor came out of medical superintendents - role of certification, leadership, medical assessment and GP.
  - Mentally ill transferred to local psychiatric hospital
- 1977 - formal advice of local medical officer to Health Authority that closure of Mental Handicap Hospitals would lead to the abolition of the post of Psychiatrist - no need to replace post.
- 1970's specialist section was dying

1970's move to psychiatry of Mental Handicap.
- Jettisoned the LD Hospital GP/Physician.
- Stayed in safety - in the group
  - But took time to take the rest of the old team with us
    - In fact have we??
  - We moved into the community CLDT
    - But what has this become.
Dissolving specialism

- Still identified by the patients we diagnose as ‘our group’ and then provide care for - as such rely on them being excluded, rather than included in other services.
- Not identified by our our skills or expertise. What we do is defined by needs of the patient group (now of Intellectual Disability) who we choose to provide medical services for if commissioned.

Change of a specialism

The commissioners key
- But short term life expectancy
- Rarely much knowledge of shop face.
- Social services, primary health and mental health
- Redefining service carries risk of more holes in service.
A Local Example

Local experience
• CLDT kept in PCT now in Community Interest Company
• mental health part of CLDT identified as Psychiatrist and A&T service - move to mental health.

• Commissioners reorganise responsibility.
  • Mental Health Commissioning to include ID Mental Health [thats why transferred psychiatrists there].
  • ID commissioners to deal with rest.
  • ?where are the community mental health nurses and other service funded?

Bristol mental health split into 16 subcontracts.
• Old Age Psychiatry reformed into functional (merged with AWA) and organic (all ages).
• ADHD services and Adult Autism Teams developed - and each cater for 2 times the population of ID.
• Being asked to take on autism/ADHD in ID - for equality.
• Different provider to the CLDT's provider - will they say yes?

So where are we going

Are we still in the shadow and imprint of the old colonies?

We still refuse to work with other disabled groups who need the same skills but would not have been admitted to the LD hospitals.

When do we start to look at what our skills are, what we provide that a general psychiatrist cannot and where that can be?

We are now going to become DID psychiatrists, part of the Neurodevelopmental Disorders. But general psychiatrists to deal with the rest of the neurodevelopment conditions excluding our area of DID.

The faculty has published a report:
  Future role of psychiatrists working with people with learning disability.

When is College going to issue a report on the skills of the ID psychiatrist and how it can contribute to other services given the new commissioning era?