Paper Title: Increasing Community Integration and Inclusion for People with l.d.

Researchers:~Thorn, Pittman, Myers, Slaughter,
University of South Florida

Focus :
The work examined "an approach to changing the systems and culture at a large residential setting" in transitioning people to community-based living settings.

Indicators Measured:
Community Presence
Community Participation
Community Integration
Community Inclusion
(Definitions at 2.4)

Introduction Summary / Historical context:

Medical Model with theories of treatments; community contact discouraged leading to segregated provision in congregate settings.
Consequences were people with a l.d. feeling devalued, disadvantaged and treated as eternal children (Service, Society, and even by parents and family)
The literature review indicated that the deinstitutionalisation process embarked on in recent decades has not delivered equally for all. People with more complex needs, dual diagnosis / mental health or behavioural issues doing less well and being less likely to make a move to a more open setting (See also The Impact of P.C.P. Emmerson and Robertson U.K.)

Historically opportunities for learning were of necessity offered in artificial non-natural settings with little chance to try out in the real world. A scatter gun approach was the accepted philosophy; if you give a blast of skill shot something will probably hit target and stick somewhere.
This has progress to starting with the person, learning about them and what they wish for in life and tailoring individual supports and skill teaching to help them to achieve their personal goals.,

Research Design:
Aim was "to design a functional system ……that would increase community integration learning opportunities". The research was designed as a longitudinal process which "examined" the effects of community focused intervention initiatives on the indices noted above. The project defined community based living as; " living in an integrated community with six or less individuals"

Research Context and Setting:

Implemented at a large residential facility established in 1921which originally was structured and functioned as an institution. The activities were centred around farming and contributing to sustainability of the institution. In latter decades activities had little personal functional or developmental value e.g. van rides out.

Another factor noted at the outset were the arduous and time consuming systems of accountability requirement, acknowledging and simplifying these was part of the conscious disposition in which the task was approached.

The transition process to community living commenced in 2004 /05. The research project commence in 2006 and gathered data for a further 15 months of transition and a 9 months maintenance period.

Participants: (2004)

At onset 556 residents on site

9 (1.6%) with Mild l.d.
32(5.7%) with Mod. L.d.
69(12%) with Severe l.d.
418 (75%) with profound l.d.
28(5%) unspecified

The Intervention researched:

A "Therapeutic Milieu" was created to focus on the relationship (therapeutic) between staff and client in the provision of new learning opportunities. The day service was used to teach in a classroom setting skills which would be needed in community and new home and these were generalised in the evenings in the new settings. This seemed to be a preparatory phase with a type of relational anchoring to a staff person, this was followed by other phases of increased community presence and participation. Staff were mentored in personalising goals and implementing a plan to achieve a goal assessed as necessary. This "Therapeutic Milieu" was a key concept in "creating the environmental and cultural change for everyone involved". This Therapeutic Milieu and was research referenced.

There were elements of review, training, and restructuring of processes followed by further phases of implementation

(Analogous to an action research cycle although not noted as such).

Key Changes at Phase 1 Community Presence:

- Acknowledged as only a step along the community route
- Relaxed or removed the old institutional requirements for going out in the community around accountability for where people are at all times, use of vehicles, and accounting for personal monies.
- Introduced more flexible staff rostering.

Phase Two Community Participation Key Actions / Changes:

- Staff supported and trained from a practice of simply going to community activities to "socially interacting with people in the community"
- To look for community opportunities which could support a known preference of the person.
- A quick reference card for clients introduced which identified the current key functional skill that was important to the person and which could be generalised in community settings.

Results Reported:

The simplification of arduous accountability systems, the retraining and mentoring of staff and the introduction of more flexible work practices led to a doubling of "Community Presence Initiative" in quarter 2 and 3 of project.
Sustainability prospects were considered good as staff were being trained and supported in using their skills to identify individual needs and opportunity and to build a support plan to address in house and in the community.

- The service introduced and used the C.Q.L. outcomes and supports measures to validate participation and interaction in community and these were used as the data set for Community Participation Indices.
- Participate in community, Quarter 3 to Quarter 8 moved from 5% to 50%
- Interact with Community, Quarter 3 o Quarter 8 moved from 10% to 70%
- Community Based Social Roles, Quarter 3 to Quarter 8 moved from 5% to 35%

Researchers Discussion:

- Data indicated significant enhancements in key community indices.
- Making the decision to change from Institution to Community in itself brings benefits
- Main focus of work was on systems and staff culture and more detailed and focused study should follow up on other aspects of the experience which were not measured or captured in the research
- The results validate the Therapeutic Milieu approach.
- Maintenance over time needs further thought and measuring

Thoughts:
Very ambitious transition to have achieved in 4 years with the results reported.
No discussion re community preparation or geographic and demographic aspects of catchment area.
No mention of significant others, family, advocates, multi-D roles, neighbours.
Emphasis on goals leading individual plans, do goals arise from a personal vision?
Would a personal vision be worth considering?
Query re general validity of the Therapeutic Milieu as a tool / process, possibly well tailored to an initial necessity to move many people in a short time frame.