

Making Life Good in the Community

Presentation Notes 10/07/2009

Making Life Good in the Community

***Building inclusive
communities:***

***Facilitating community
participation for people
with severe intellectual
disabilities***

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Background to report

- *Report considers issues raised by 2 ½ years **action research project** in group home for five men with severe intellectual disabilities*
- ***Researchers perspective** – that goal of building inclusive communities involves concepts often poorly understood, hard to define, difficult to apply*
- *Report critically examines premises and complexities, assumptions and practices that underpin efforts to reach **goal of building inclusive communities***

Thinking underpinning report

- *Consensus - most people with intellectual disabilities **physically present in community – but not participating***
- *Most have **small and highly restricted social networks** = characterised by interactions with other people with intellectual disabilities, service workers, immediate family member*
- *Contact with ‘non – disabled’ most likely to be **mundane, impersonal, fleeting***

Thinking underpinning report

- *Concept of - ‘**distinct social space**’ to refer to generalised pattern of social relationships typical of many people with intellectual disabilities*
- *Suggests that actions of human service organisations and staff can **influence boundaries of such relationships***
- *Can be strengthened or weakened, enlarged or contracted - **people can be helped to cross them***

Thinking underpinning report

- *Research used John O' Brien's (1987) **distinction between community presence and community participation as orientating concept***
- *O' Brien – people should be supported to increase number and variety of 'ordinary places' they know and can access = **community presence***

Thinking underpinning report

- *Even if **community presence** occurs – people can still remain in ‘**distinct social space**’ e.g. going to ordinary places in company of other service – users, staff, immediate family members*
- *Goal of **community participation** – to expand restricted social networks to include ‘non – disabled’ people, so individuals can experience being part of **growing network of personal relationships that include close friends***

Thinking underpinning report

- ***Specific research goal*** – to understand how staff in group home could be supported to expand men's social networks with 'non – disabled' people
- ***Report sets out argument*** – that facilitating relationships with 'non – disabled' people a prerequisite to realising goal of building inclusive communities - seen as crucial point often missed and not made explicit
- ***Not logically inconsistent*** - to want to facilitate relationships with non – disabled people and also support and encourage relationships between people with intellectual disabilities

Thinking underpinning report

- *Both **type** of disability and **level** of disability have implications for goal of building inclusive communities*
- *Realising goal likely to be **harder for people with severe disabilities** – generally have more limited social lives*
- ***Level of disability** has implications for staff practice, family members views, reaction of general public*

Findings – 1. Goal and level of disability

- ***Building inclusive communities*** (goal) harder for people with severe disabilities – but should not be excluded from goal
- ***Useful focus*** to learn from struggle to realise goal
- ***Highlighting level of disability as important variable*** brings important issues to foreground

Findings – 1. Goal and level of disability

- ✓ *People with severe disabilities not likely to understand what **abstract goal of building inclusive communities** means + not able to express opinion*
- ✓ ***Abstract ideas** that underpin goal may be viewed by some as irrelevant/of less importance to people with severe disabilities*
- ✓ *Some human service workers may believe in importance of goal but **struggling to realise it** in lives of people they are supporting*

Findings – 2. Enabling community presence

- ***Staff focus on increasing number/variety of ordinary places that five men know and access***
- *Led to wider range of activities in community – gave men **greater community presence** than had been case*
- *Though important – this focus alone **unlikely to result in community participation***

Findings – 2. Enabling community presence

- *Supporting individuals to activities in ‘ordinary’ settings not same as supporting to establish relationships with people without disabilities*
- ***Community participation unlikely to be outcome of community presence per se***
- *Neither existing training nor specific transition training gave staff much understanding that **part of role** is to facilitate relationships with non – disabled people*

Findings – 2. Enabling community presence

*As part of **deinstitutionalisation initiative** funding provided to employ staff to support community inclusion and active support approaches*

- Researchers worked for 22 months with staff about their understanding of inclusive communities*
- Supported staff to think about planning individual activities where **community inclusion** more likely outcome*

Findings – 2. Enabling community presence

- ***By end of 9 months - pattern of supporting activities that led to community presence rather than community participation not changed***
- ***Staff still held differing views about feasibility of building inclusive communities for the men and the meaning of participation***
- ***House supervisor changed and new strategy for several residents – development of **detailed social network map** adopted to support staff to think about potential activities***

Findings – 2. Enabling community presence

- *At conclusion 13 months later individual activities for four residents had been trialled*
- *Final evaluation concluded that three of four activities had little potential for facilitating community participation*
- ***They merely continued pattern of community presence***

Findings – 2. Enabling community presence

Findings show enormity of task of developing inclusive communities for people with severe intellectual disability

- ***Key finding – that type of activities that people did + way in which they were supported = important factors in increasing likelihood of community participation as outcome***

Findings – 3. Creating/unmaking of ‘distinct social space’

*People with severe disabilities **rely on others to greater degree** - to plan/organise access to community facilities*

- *Therefore **staff practice an important variable** – has been shown to be associated with variations in outcomes for people living in group homes*

Findings – 2. Creating/unmaking of ‘distinct social space’

- ***Research found - organisation of services + staff practices significant contributors to creation and maintenance of ‘distinct social space’***
- *But also has active role in breaking out of ‘distinct social space’*
- ***Ensured five men spent lot of time with one another***

Findings – 3. Creating/unmaking of ‘distinct social space’

Underpinned by –

- ✓ *service – centred thinking*
- ✓ *emphasis on bonding rather than bridging relationships*
- ✓ *‘inward – looking’ tendency that resulted in group outings and the ‘privileging’ of staff – resident relationships*
- ✓ *failure to consider ‘natural’ supports*

Findings – 4. Attitudes to building communities + ID

- ***Findings suggested - attitudes, to people with severe intellectual disabilities and to goal of building inclusive communities very important influences on staff practice***
- ***Label of ‘severe intellectual disability’ strongly implicated in determining staff perceptions and reactions of non – disabled people***
- ***An important factor in how men’s lives were organised at home, where spent weekdays, how made use of leisure time***

Findings – 5. Attitudes of non – disabled people

- *Staff had strong views about attitudes of...saw as barrier to goal of building inclusive communities*
- *Though negative attitudes of...are a problem – number of important issues about **way staff frame and react to peoples attitudes***

Findings – 5. Attitudes of non – disabled people

- *First – hand **experience of indifferent or negative interactions** likely to have impact on staff’s perception, willingness, motivation to build inclusive communities*
- *Unless staff have certain **tenacity, resilience, or work environment** designed to identify and work with negative feelings that arise, then feelings may make staff less likely act as facilitators*
- *Does seem to be important to state that people with ...limited by personal restrictions of their disability, have features others with little or limited direct experiences of disability may find disconcerting – **only by acknowledging can we think about how to address issues related to these factors***

Findings – 5. Attitudes of non – disabled people

- ***Task of building inclusive communities not to be underestimated***
- *Will require enhancement of role played by non – disabled public – a role they have not in general, actively asked for*
- ***Direct support staff being given disproportionate responsibility for achieving goal***
- *A role for which they are inadequately trained and supported*

Findings – 6. An important prerequisite

- ***For realising goal of building inclusive communities***
– to develop common vocabulary for the concepts people use
- ***Accepted definition of what goal means*** – *absence of common vocabulary and shared understanding of goal major obstacle to achieving it*
- *And include recognition of the **multi faceted strategies** that must be pursued*

Findings – 6. An important prerequisite

- ***Explicit recognition*** that work at micro – level – with individual to build social networks as important as strategies at macro – level
- ***Explicit recognition*** that no staff member will understand multi – layered strategies necessary to work on goal or will have knowledge, skills, motivation to design or implement these
- ***Explicit recognition*** – is not an intuitive role – and commonsense understandings of concepts like ‘inclusion’, ‘participation’, ‘empowerment’ etc. not sufficient to realise goal

Findings – 7. Issues for policy makers

- ***Building inclusive communities a complex and multi faceted goal***
- *Any working definition will need to be nuanced concept that allows both **bonding** and **bridging relationships***
- *Will acknowledge that nothing wrong with people choosing to spend time with one another or being friends*

Findings – 7. Issues for policy makers

- *Any working definition/guidance must also **explicitly include** need to facilitate relationships between people with ..and non – disabled people*
- *When clear definition available – **key task** to develop/instil coherent planning framework that **links strategic to operational plans** ('how')*
- *So that principles underpinning strategy congruent with behaviours expected of direct support staff + methods they apply*

Findings – 8. Planning

- *Plans to realise building inclusive communities - **unlikely to be successful** if people expected to meet goal unaware of what it encompasses and implications*
- *Includes **staff** making plans with **limited understanding** of goal and implications*
- *Includes staff given partial feedback about progress towards goal from **senior staff/managers** with equally **limited understanding** of goal and implications*

Findings – 8. Planning

- ***Both levels frequently confusing community participation and community presence***
- ***Progress towards achieving goal requiring leadership + commitment at all levels***
- ***Focus of research at house level – findings reveal number of implications related to internal leadership of a group home***

Findings – 8. Planning

- ***‘House supervisors’*** role central to realising goal...because person has **big influence on how direct support staff actually behave**
- ***‘House supervisors’*** - practice leaders with key role in supporting effective performance of staff they manage – must provide support, direction and coaching
- ***‘House supervisors’*** - need specific knowledge, skills, abilities in relation to goal...must be clear about what goal means for support workers...as must agency

Findings – 8. Planning

- ***Need to anticipate staffs ‘objections’ (difficulties with) to goal...have well – prepared counter – arguments to persuade of benefits of facilitating relationships with non – disabled people***
- ***Also be able to actively engage with ‘tensions’ within complex ideas and perspectives... if to act in informed way***

Findings – 9. Organisational stability

- *Provision of **stable, skilled workforce** integral to provision of quality services*
- *When **high turnover...staffing issues** ...complex issues e.g. goal... move in/out of focus*
- ***Stability at team manager and house supervisor** levels improves chances of better supervision, providing platform for consistent communication, planning, follow-through*

Findings – 10. Enhancing organisational capacity

- ***Organisations have finite capacity for pursuing their goals***
- ***Overly focusing on **community presence** may leave limited/no time for facilitating **community participation*****
- ***Important that staff efforts to enhance community presence not stopped... but that staff supplement with supporting community participation***

Findings – 10. Enhancing organisational capacity

- ***Community participation not a day – to – day priority for many staff...ways need to found of bringing into focus...making sure time allocated to work at it***
- ***Direct support staff must understand **role to include** facilitating society's responses to people***
- ***Job descriptions need to emphasise educational and facilitative role that makes use of 'natural' supports***
- ***Boundaries of staff/service user relationship need to be clarified...staff relationships inextricably linked to service users quality of life...could act as conduits...linking people to social networks***

Findings – 11. Enhancing community participation

- ***Report distinguishes*** between circumstances when acquaintances likely to remain as...and situations where might be possible to move from ***acquaintance to friendship***
- ***Relationships more likely*** - when people participating in recurring activities, over extended period, where social interaction possibilities high

Findings – 11. Enhancing community participation

- ***Staff needing to support people - to go to places where relationships more likely to happen***
- ***In places where - same people can meet routinely so can make judgment whether want to spend time with one another***
- ***Staff needing to learn to identify activities - where same people can meet routinely and where friendships more likely to happen***

Findings – 11. Enhancing community participation

- ***Staff team needing to learn*** - to adopt highly critical attitude towards own efforts to build...
- ***Needing to become good judges*** - of 'successful' community activities, learn from others and own 'mistakes'
- ***Staff indicated they did not know*** - how to facilitate relationships between people with severe intellectual disabilities and non disabled people
- ***A training and coaching need...is missing in current training programmes...not part of knowledge base of most house supervisors and senior managers***

‘Making a Good Life in the Community’

***Building inclusive communities:
Facilitating community participation for people with severe intellectual disabilities***

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1. Efforts to encourage community participation

- *Efforts unsuccessful – lessons learned – especially barriers*
- *Staff put lots of effort into increasing number/variety of ordinary places – **greater community presence***
- *But types of activities + way individuals supported meant **little potential for facilitating community participation***

1. Efforts to encourage community participation

- ***Because organisations have finite capacity for pursuing goals*** – overly focusing on ‘presence’ may leave limited/no time for facilitating ‘participation’
- ***Findings support*** - importance of ‘house supervisors’ role in influencing practice + beliefs of staff have impact on practice
- ***Findings support*** – variation in level of disability has important implications for staff practice, family views, reaction of public

2. Issues for policy makers

- *Building inclusive communities **complex and multifaceted goal***
- *No accepted definition of....*
- *Needs to be nuanced concept - **that allows both bridging and bonding relationships***
- ***Any working definition or guidance for staff - must explicitly include need to facilitate relationships with non – disabled people (bridging role)***

2. Issues for policy makers

- *Doing so does not devalue people with intellectual disabilities, nor does it attempt to privilege relationships with non – disabled people*
- *Arises from understanding that people occupy ‘**distinct social space**’ – situation not of own making*
- *Argument is direct support staff must supplement work to promote ‘**presence**’ with efforts to support ‘**participation**’*

2. Issues for policy makers

- *Staff come away from training on goal without understanding that part of role is to facilitate relationships with non – disabled people (bridging role)*
- *However the outcome of building inclusive communities still an imagined society, ‘the community of our dreams’*
- *Goal about what society and its people ought to be like*

2. Issues for policy makers

- *Research can tell something about implementing goal, nothing about **whether right goal***
- ***Absence of shared definition of goal** makes it hard to describe inclusive community, measure one, or intervene to build one*
- ***As consequence significant number of staff may not know what supposed to do or think are doing what supposed to be doing***

3. 'Distinct social space' – a useful concept?

- *Ways need to be found of translating goal and values underpinning into 'practical guides for action'*
- *'Distinct social space' - refers to pattern of relationships typical of many people with...*
- *Also concept that allows to plan, take action e.g. posits a boundary around individual neither fixed nor permanent*

3. 'Distinct social space' – useful concept?

- *Boundary denotes an inside/outside*
- ***What makes 'space' distinct*** - is that typically inside boundaries are typically only people with..., relatives, staff
- ***Outside boundaries are ...***, engaging in mundane and fleeting contact
- ***If these boundaries in state of flux*** - then actions of services and staff can influence them

3. 'Distinct social space' – useful concept?

- *If boundaries fluctuating, can be strengthened, weakened, enlarged, contracted*
- **Concept and way of thinking helps explain why 'presence' most common outcome - most of activities supported by staff support these boundaries, with few being pursued that in ways that tries to bridge or break through**
- **Only certain activities have potential for 'participation' so in most cases 'presence' is final outcome**

3. ‘Distinct social space’ – useful concept?

- *‘Default position’ of staff = the automatic practices adopted by staff when no alternative specified*
- *Variable staff have some control over is - **own behaviour***
- **Good question** – *‘what effect does what I am doing, or what we are doing, have on a person’s social space’?*

3. 'Distinct social space' – useful concept?

- ***Proposition that** – rather than state as absolute position that services segregate and isolate people...we can understand that **actions of human services employees** - can both strengthen or weaken boundaries, contract or enlarge them, make less or more permeable*
- ***Rather than describing peoples lives in absolute terms** - being 'included' or 'excluded', we can understand lives as really are – complex web of 'inclusionary' and 'exclusionary' situations and experiences*

3. 'Distinct social space' – useful concept?

- ***Understanding boundaries in this way – makes easier to see need to move beyond service – based supports – discover how to make use of 'natural supports'***
- ***Must be acknowledged - making use of 'natural supports' hard and 'problematic'***
- ***Because it means enhancing role played by members of general public***

- Goal is attempt to shape and control public attitudes towards people...
- Policies of social inclusion have not been response to popular demand
- If we exclude staff working for services... then non – disabled people have not demanded that people with... have access to sport centres, cinemas, cafes or supermarkets
- Nor have lobbied for close relationship with...

3. ***‘Distinct social space’ – useful concept?***

- *As things stand – **unlikely to be outcry from non – disabled people** if don’t have close relationship with person with...*
- ***Worst stories told by staff** - after they step outside front door are experiences of isolation, rejection, hostility and avoidance*
- *Unless staff have certain **tenacity/resilience + work environment** designed to identify and work with **emotional distress/negative feelings that arise**, then may become less rather than more likely to act as **facilitators***

4. Keeping a systemic approach

- **Everything affects everything else** - *everything is part of something bigger and nothing can stand on its own or be understood on its own*
- **Behaviour of staff** - *needs to be understood in context of employing organisation*
- **Human service organisations** - *need to be located/understood in broader social context*

5. Organisational capacity

- ***Organisations have limited capacity to achieve goals***
- ***‘Building inclusive communities’ is one goal and ‘participation’ one facet of that goal***
- ***Drawing a distinction between what needs to be done and where there is greater choice – may be useful in suggesting why so little progress made towards ‘participation’***

5. Organisational capacity

- *Significant proportion of staff time taken up with 'needs to be done' – food must be bought, cooked, eaten, dishes washed*
- *People must be helped wash, dress, etc.*
- *Number of organisational tasks given importance e.g. **administrative tasks***
- *People must be driven to...picked up...get haircut, buy shoes, visit GP*

5. Organisational capacity

- *All ‘needs to be done’ reduces amount of time ‘available’ where people truly free to decide how to spend it*
- *Reduces time available to work at ‘participation’*
- *‘Inclusion’ requires focused effort’ (O’Brien 1987)*
- *‘Participation’ unlikely to happen - the more time spent engaging in activities that lead to community presence*

5. Organisational capacity

- *Given that **organisational capacity limited** – and **‘participation’ not day – to – day priority** for many staff, ways need to be found of bringing it into focus – making sure time allocated for **‘focused effort’***
- ***PCP may help in this regard***
- ***As well as staff putting ‘focused effort’** – other ways include **creation of specific roles** to work with small number of people and creation of **‘circles of support’***

6. Organisation of resources

- *High quality services need adequate resources and those **resources need to be well – organised and flexible***
- ***Fixed roster** - more likely to be staff – centred – determines the activities that can be supported on particular day, but also determines which member of staff supports an activity*
- ***How activities supported** - likely to have impact on whether outcome is ‘participation’ and **in particular** whether move from acquaintance to friendship has any likelihood of happening*

6. *Organisation of resources*

- *Greater flexibility needed - in deployment of staff planned around activities more likely to lead to 'participation'*
- *Direct support staff - has much better chance of acting like facilitator when support same person in same setting over period of time*
- *Gets to know a setting, people who go there, how person behaves and interacts with people in that setting*

7. Organisational stability

- **Importance of creating stability in particular roles** - 'house supervisor' and manager
- **Community participation** - requires medium to long – term planning and continuity of support
- **Goal also requires leadership at both these levels**
- **Consistency increases chances** - of good supervision, provides platform for consistent communication of expectations and feedback, better follow through
- **High numbers of casual and temporary staff having to be managed and rostered** - means focus moves away from issues requiring long – term planning to 'keeping things going' and 'avoiding major incidents'

8. Importance of 'internal' leadership

- ***Findings lend support to proposition that - a 'house supervisor' can have big influence on practice of direct support staff***
- ***Findings also reveal limitations of 'outsiders' as change agents in group homes - which are relatively isolated and semi – autonomous settings***
- ***'Outsiders' can offer external challenge - but limited in amount of monitoring and support can offer***
- ***Day to day practice in group homes can be insulated from organisational goal***

8. Importance of 'internal' leadership

- *In most organisations **how staff actually behaves** - related to 'leadership' of person's immediate supervisor*
- *'House supervisors' should understand they **are practice leaders** - with key role supporting performance of direct support staff they manage*
- ***A prerequisite is** - being clear about what goal actually means*

8. Importance of 'internal' leadership

- ***Until research supervisor/staff did not know - were meant to be supporting community participation...had not received any feedback on practice***
- ***Staff often left to own devices when more direct leadership style required***

9. Issues for 'house supervisors'

- *Is important they adopt **situational management style***
- *But also that should not shy away from more '**directive behaviour**' where goal concerned*
- *May be case that many staff not have **knowledge, skills or abilities to competently tackle goal...may be lacking in commitment to goal***

9. *Issues for 'house supervisors'*

- *In such circumstances - telling people what to do, how to do it, where to do it, when to do it, then supervising performance might be appropriate*
- *May help avoid endless cycles of experiential learning - where same mistakes played out again and again*
- *Findings suggest that goal requires theoretical framework + that 'lay' understandings of terms like 'inclusion' and 'participation' inadequate*

9. Issues for 'house supervisors'

- *'House supervisors' also need **skills in managing conflict** – not something to be shied away from but frequently is*

10. Direct support – Role clarity and developing reflective skills

- ***Staff did not see selves as having active role in educating community – expected would be done by other unspecified people***
- ***Shift from service – centred to supports model - requires **different mindset** about direct support role***
- ***Contemporary thinking emphasises strong educational and facilitative role***

10. Direct support – role clarity and developing reflective skills

- ***Job description needs to reflect this***
- ***Clear message needs to be given to staff about ‘type’ of relationship they should have with people***
- ***‘Participation’ can be enhanced if staff act as ‘conduits’ e.g. linking people to own social networks***

10. *Direct support role*

- *Limited amount of reflective space exists for staff to discuss practice issues – recurrent finding*
- *Strong suggestion from research - that better outcomes more likely if staff can critically engage with ideas behind goal + own actions in relation to it*
- *If staff to act in informed ways need be able to **actively engage with the tensions within the complex ideas and perspectives involved in goal***

10. Direct support role

- *Especially true for those in **supervisory positions***
- *When ‘participation’ a specific goal - staff urged to critique their ideas strongly at beginning of planning process*
- *Not when have invested lot of energy...taken number of steps down particular path*

10. Direct support role

- **When making judgement about type of community are engaging with or facilitating...issues that are important**
- ✓ Is the activity that has been selected one where community participation has greater likelihood of happening?
- ✓ Does it involve place where same people can meet routinely so can make judgement whether want to spend time with one another?
- ✓ Does it allow non – disabled people to have direct experience of people with intellectual disabilities so can gain familiarity?
- ✓ Is it an activity where social interaction high?

11. Impact of severe intellectual disability

- ***Assumptions*** that are held about people with ... are important – **have impact** on how people relate to one another
- Terms like engagement, inclusion, involvement, participation, **often poorly understood** and implemented by front – line staff
- *Is necessary to acknowledge the personal restrictions of severe impairment*

11. Impact of...

Seems helpful to acknowledge that people with

...

- *Do not understand what **abstract concepts**, such as goal or ‘participation’ mean*
- *Are **at risk of** not having concepts applied to them*
- *Live in world where non – disabled people can at times be indifferent or hostile*

11. Impact of...

- *May have more difficulty providing the **reciprocity needed** to maintain relationships*
- *May partake atypically in ordinary settings*
- *Rely on others to plan and organise their lives*

11. Impact of ...

*As consequence of severe... **individuals supporting** exercise great control over lives...and some*

- Do not see goal as being relevant*
- Struggle to apply them to people they support*
- Are more or less willing and capable of identifying potential activities that support 'participation'*

11. Impact of ...

- *Significant number hold world view based on **practicality v universal rights***
- ***Power of 'label'** to determine perceptions so strong makes it hard to see individual in any other way*
- *May not have **knowledge, skills, abilities** to engender 'participation' for people*

11. Impact of ...

Training implications – may be helpful to focus on

- *Difficulties non – disabled people experience when first encounter people...*
- *Strategies related to what staff might do after introductions made*
- *Preparing people for atypical behaviours*
- *Modelling ways of engaging with people with ...*

11. *Impact of ...*

- *Researchers reached point - where had addressed barriers to 'participation' and staff had begun to support individual activities where expanding social networks had become a possibility*
- *The length of time it took to do this precluded possibility of learning about these training and coaching issues – those related to what staff might do when people have said 'hello'*
- *Seems to be important area where future research might help to reveal some practical guidance*

Question – is building inclusive communities a possibility?

- *Story of **building inclusive communities** at... was about **conflict**... where arguments, disagreements and misunderstandings integral part of narrative*
- ***Goal** is key part of most industrialised countries social policy ‘vision’ for people...*
- *Issues in report help illuminate why **only modest progress made in enabling community participation in last 30 years***

Question

- *Unless more time and focused effort is put into discovering whether we can build inclusive communities on a large scale then the question is likely to remain unanswered*

