

# Papers Reviewed

“The Features of Short-break Residential Services Valued by Families Who Have Children with Multiple Disabilities”

Roy McConkey, Maria Truesdale and Chris Conliffe

“The barriers to social inclusion as perceived by people with intellectual disabilities”

Suzanne Abbott and Roy McConkey



# Common theme

- The key importance of inclusion of the **voice and views of the person and the family** in the design and delivery of services, and in policy formulation

# Paper 1

*“The Features of Short-break Residential Services Valued by Families Who Have Children with Multiple Disabilities”*

Roy McConkey, Maria Truesdale and Chris Conliffe  
*Journal of Social Work* 2004; 4; 61

# Background & Context

- Traditionally 'respite' came from recognising the need to provide carers with a break from the responsibilities of caring for a child with disability
- Now moving to a model which aims to provide the child / adult with:
  - Opportunities for increased inclusion
  - A widened range of activities
  - Increased quality of life
  - Social integration into the community
- Move to meeting needs of child and family - 'respite' to 'short breaks'

# Background & Context

- However, “evidence is ambiguous as to the beneficial effects on carers well-being of having respite breaks as compared to those carers who do not” (Nally 1999)
  - Methodological weakness of previous studies
  - Lack of agreed quality standards

*“It is not the provision of respite breaks per se that is important to carers, rather the nature and quality of such breaks”*

# Background & Context

## ➤ Types available:

- Stays in residential homes or hospital settings
- Child stays with a host family
- As part of a residential holiday
- Supervised leisure activities during school holidays / after school / weekends

# Background & Context

- Challenges of tailoring short breaks to the needs of both the child and family
  - Demand usually exceeds supply
  - In some areas there is only type of service available
  - However, if the needs are not matched it can be cost ineffective, since some lower cost breaks are better suited to some families

# Study Aims

## Aims:

- To identify the features of short break residential services that *families* value
- To use this information as a yardstick when commissioning and evaluating short break services



# Methods


## Phase 1

- 108 parents of children <19yrs with multiple disabilities incl. severe learning disabilities
- From urban & rural areas
- Open questions about their experiences of short break services
- Thematic Analysis, validated at a consultation seminar of carers and professionals

## Phase 2

- 59 parents used items derived in Phase 1 to evaluate 3 short break services

# Questions

- What are the main benefits of the short break service to you as a carer?
  - What are the main benefits to the child?
  - What do you like most about the service?
  - What would you like to improve?
- 

# Results

## 4 main themes as benefits for carers

- Break from demands and routines of caring
- A chance to spend time with other family members
- Opportunities to do things they could not otherwise do
- Having rest, relaxation and sleep

*“Gives me time to relax. I have peace of mind knowing that N is in safe hands; there is only certain people that N will relate to”*

# Results

## Benefits for child, in parent's opinion:

- Opportunity to interact socially with others
- Different environment
- Child enjoying the break
- Getting used to being away from home and more independent
- Being able to go on outing and join in different activities

# Results

## ➤ Positive aspects of service

- Friendly staff
- Homely
- Well cared for

## ➤ Improvements suggested for service

- Greater availability
- [No improvement needed]
- Accommodate children with similar abilities
- Make it more homely
- Staff turnover
- Cater for family emergencies

# Results

## Aim of Phase 2 –

- To determine if the features of a ‘good short break service’ discriminated among different services
- Items rated by 59 parents for 3 services (True for this service, somewhat true for this service, no not true for this service)
- Services:
  - Flat beside clinic
  - House in an affluent residential area
  - Villa on hospital grounds

# Results

- Item analysis carried out to identify items that significantly discriminated across services
- Non parametric chi-squared tests
- 17 items discriminated
  - Services features
  - Benefits to child
  - Benefits to carers
- Many items common to all services (e.g. *'parents get a break'*)

**Table 3 The percentage of parents rating 'yes' to each item for the three services**

Item	Service A (N = 31)	Service B (N = 34)	Service C (N = 22)	Chi- sq	Factor loading
<b><i>Service features</i></b>					
Small numbers of children at a time	97	100	57	29.3	0.940
Homely environment	100	100	36	42.8	0.926
Located in pleasant surroundings	100	100	46	36.1	0.814
Low risk of abuse	97	100	56	25.5	0.806
Child looks forward to going	69	83	20	15.3	0.805
Child-orientated service	100	100	80	13.2	0.759
Standard of care provided	97	92	67	13.1	0.726
Gives me someone to talk to	74	50	32	21.6	0.691
<b><i>Benefits to the child</i></b>					
Children are shown love and affection	71	97	36	29.6	0.943
Stimulation and activities for the children	71	87	35	22.5	0.943
<b><i>Benefits to the parent</i></b>					
I meet other parents	68	27	9	26.1	0.816
Told about other services	65	36	9	17.2	0.700

NB All chi-sq tests were significant  $p < 0.01$ . The items are arranged in order of loading on the Factor Analysis with highest loading items first



# Discussion & Conclusions

- The study identified variance in the preferences and experiences of families
- It highlighted the 'hidden benefits' of short breaks – opportunities to build trusted relationships, meet other parents, get information about other services
- These outcomes are accentuated when services are provided locally and within easy reach of the family home
- Providers need to plan for needs beyond those of providing a break

# Conclusions

- There would be cost implications to meet with the needs expressed – e.g. better access to transport, playrooms, extra staffing focused on the needs of child
- There are conflicts between some of the elements valued (*e.g. match children's vs greater availability*)
- *Therefore a choice of options will continued to be required within a wider geographical area*
- This parallels the findings that were previously made for long stay residential placements.

# Conclusions

- Short breaks mean different things to different parents so in order to provide a quality service and meet parent satisfaction, services must understand families needs
- A delicate balancing act between the needs of child and parent – challenge to identify children's preferences
- There are resource implications
- When demand exceeds supply ensure some help for *all* families
- Features identified by the study can be incorporated into all types of provision
  - Leisure and befriending schemes
  - Breaks with host families
  - Domiciliary support schemes
- Goal is to be **flexible, person-centred, and imaginative**

# Paper 2

*“The barriers to social inclusion as perceived by people with intellectual disabilities”*

Suzanne Abbott and Roy McConkey

*Journal of Intellectual Disabilities 2006; 10; 275*



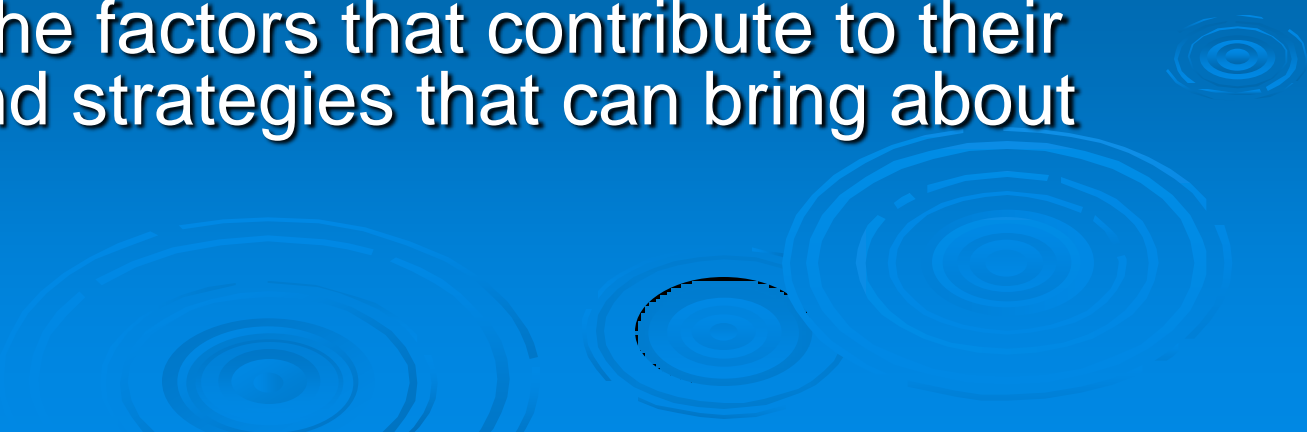
# Introduction

- Study conducted as part of the 'At Home in the Community Project' – 3 year study funded by Tiangle Housing Association
- Carried out in Northern Ireland, 2006
- This presentation will concentrate on the barriers to social inclusion specifically as they relate to living options

# Policy and Context

- **'Inclusion'** is one of the 4 key principles of UK Government policy for future service provision for people with intellectual disabilities
- Definition of Social Inclusion in disability context:  
*"Greater participation in community-based activities and a broader social network"*
- 'Valuing People' (2001) recognises
  - *"housing can be the key to achieving social inclusion"*
  - Objective for people with ID and their families *'to have greater choice and control over where and how they live'*
- There are, however many other factors that affect social inclusion – physical presence within a community does not guarantee greater social inclusion

# Rationale

- Ample evidence of social exclusion of people with disabilities, and people with ID in particular
  - The voice of people with intellectual disabilities has been absent in debates as to how social inclusion can be made a reality
  - Basic requirement for advocates to have an insight into the factors that contribute to their exclusion and strategies that can bring about change
- 

# Study Aims

## Aim:

To gain an insight into how people with ID who lived mainly in supported housing perceived the barriers to their social inclusion and the ways these barriers could be lessened or removed.

## Objectives:

To support greater advocacy by those service users at both an individual and a group level

To challenge service managers and support staff to review the strategies they use (or fail to use) to support social inclusion



# Methods

- 6 focus groups of between 10 and 20 people (n=68) living in:
  - Supported living schemes (55%)
  - Tenants in group homes (36%)
  - Registered residential homes (9%)
- Mixture of communication styles and support measures at the focus groups
- *(Q – with supporters present is there a risk of restricting information giving?)*
- Focus group dynamics an opportunity for peer support

# Methods (cont)

- 4/5 hour workshops
- Topic of 'Social Inclusion' introduced through photographs of people engaged in community activities
- **Questions:**
  - What activities do you enjoy doing or would you like to do near where you live? Why is this?
  - What helps you get involved in those activities
  - How can staff and the service manager help you more?
- **2<sup>nd</sup> session**
  - What stops you from doing community activities and solutions to overcome these problems
- Information from smaller groups (4-5 people) with a facilitator fed back to wider group

# Results

- Latent content analysis to identify themes of what social inclusion meant to the participants:
  - Talking to people
    - *saying hello to people*
    - *meeting people when you are out*
  - Being Accepted
    - *I'd like not to be made to feel different... and to feel safe*

# Results (contd)

- Using community facilities
  - *living near to town centre, shops, schools, church, GP – location of home & proximity of services;*
  - *cost of transport a key to accessing community amenities*
- Opportunities
  - *staff availability within the living option affects person's ability to take part in activities;*
  - *policies on visitors coming to a person's home affects friendships*

# Barriers to Social Inclusion

## Personal abilities and skills

- Lack of self-motivation/confidence
- Lack of knowledge about healthy living
- Poor literacy and numeracy skills
- Poor knowledge of the area

## Staff and management

- Not allowed to go out alone or make your own plans
- Not treated as an adult
- Short staffed
- Not enough one-to-one staff time

## The community

- Negative attitude of the community
- No information available on activities/events
- Not enough activities available
- Few links with the home/scheme
- Availability and access to work placements
- Not enough advocacy and volunteer groups

## The home/scheme

- Location
- Lack of accessible and affordable transport
- No company to go 'out' with
- Few community activities/facilities available to join in with

# Suggestions to overcome Social Inclusion

## Personal ability and skills

- Access to appropriate skills training (literacy, numeracy, budgeting, independent travel)
- Getting to know the neighbourhood
- Encouragement from staff to socialize
- Access and encouragement towards a healthy lifestyle/information

## Staff and management

- Being listened to by staff and managers
- Support to be able to make your own plans and go out independently
- More staff available for one-to-one
- Better use of available advocacy and volunteer groups to accompany individuals
- Up-to-date information on community opportunities
- Enabled to live independently

## The community

- Education of the community – schools etc.
- Accessible information provided on activities/events
- Make links with community through open days in services
- More advocates and volunteers to accompany individuals
- Increased use of existing (mainstream) facilities and activities

## The home/scheme

- Use of a named driver or known local taxi firm
- Support to access activities available locally
- Free/affordable/accessible transport options
- Taught/allowed to use public transport

# Discussion & Conclusions

- Participants in the study recounted positive and negative experiences in relation to each of the themes
- Participants were able to identify the barriers they had experienced to social inclusion and could articulate ways of reducing or removing them.
- The study brings a new dimension to our understanding of planning and delivering quality livign options:
  - the voice of people with intellectual disabilities is extremely important in formulating policy and service planning/delivery
  - it is very important that strategies are employed to widely disseminate policies in accessible formats

# Discussion & Conclusions

- In relation to living options specifically, *“a basic starting point is for planners to consider the availability of community amenities or public transport when developing or choosing accommodation”*
- Facilitating people visiting at home is an underused strategy for social inclusion
- Methods employed in the focus groups potentially very useful for future studies to include voices of people with ID in Ireland
- Newsletter summarising the findings circulated to all participants of the project



# Republic of Ireland context

- *Needs and Abilities* (1990) is the latest Irish policy document for people with intellectual disabilities
- National Federation advocating for the need for a new vision/policy statement for Intellectual Disability in Ireland
- Discussion paper to contribute to this process developed by the National Federation for presentation to the Department of Health and Children as a reflection of what the new vision might look like and the principles that should underpin it.
- **Inclusion** one of the 5 key principles in the proposed discussion document from the National Federation – studies such as these can help us to understand how *meaningful inclusion* can be achieved