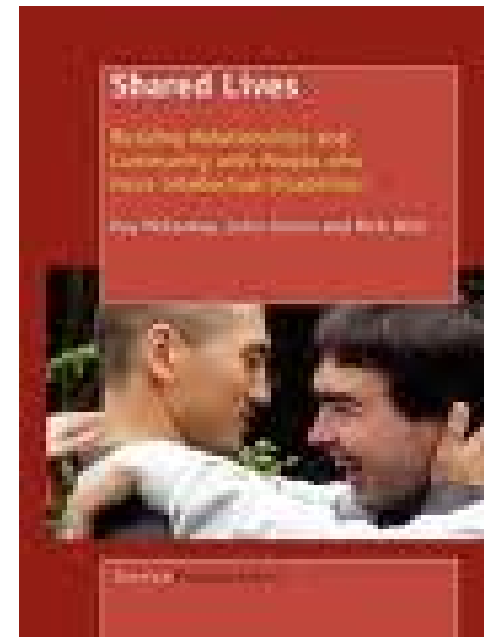


Shared Lives

Building Relationships and Community with People who have Intellectual Disabilities

By:

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- *Relationships with others lie at the very core of human existence. Humans are conceived within relationships, born into relationships and live their lives within relationships with others. Each individual's dependence on other people for the realisation of life itself, for survival during one of the longest gestation periods in the animal kingdom, for food and shelter and aid and comfort throughout the life cycle-is a fundamental fact of the human condition (Berscheid & Peplau, 1983)*

- *The foreword describes this book not only as essential reading for not only those of us committed to the respect acceptance and inclusion of people with intellectual disabilities but for anyone who works to promote the potential and self-determination of all of us*

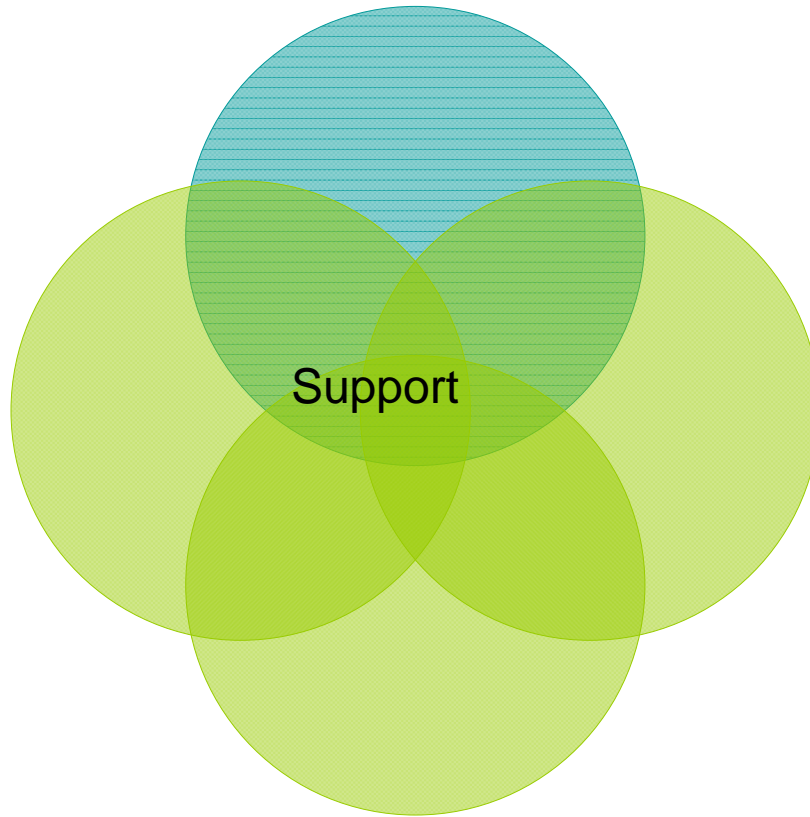
- A major theme of the book is the need to build communities of supporters from paid supporters, community supporters and family
- Supporting people to live more fulfilled lives means listening to their hopes and fears, understanding their capabilities and needs for support and helping them to realise their ambitions and cope with inevitable disappointments
- ‘the power of listening has the power to transform the relationship between supporters and the people they support’ (O’Brien 1989)

Working in partnership

Appreciating the person

Bringing people together

Nurturing
mutual relationships



- It is increasingly evident that service systems inhibit rather than encourage innovative practice by supporters.
- A secondary theme of the book is the new ways of thinking and working that are required to nurture supportive relationships in service and society
- The history of services is rooted in managing people's deficits
- A better starting point is the person

The Elements of Success

Organisers of the World Special Olympics employed the following tactics.

- Promote positive images of people
- Create positive associations
- Use ordinary settings
- Have a good time
- Expect achievement

- In the professional literature on people with intellectual disabilities little reference is made to positive qualities.
- In a total of 2,789 articles surveyed only 21 focused on anything positive. Less than 1% of articles (99+% focussed on negative features)

- A content analysis of books written by parents of children with various disabilities found that in addition to recounting significant demands and emotional stress, the majority of authors also felt that their lives had increased enrichment and meaning as a result of their experience with their children (Mullins, 1987; Hastings and Taunt 2002)

- Experience of siblings

I've become a friendly open person in a way but that wasn't there when I started. You could say I have developed that strength because of Paul...

- Experience of staff

The encounter is from person to person. The boxes that we put one another in are not there with them. They bring you somewhere deeper in yourself a place of greater humanity and vulnerability.

- These assets and gifts of people in need of support are not often acknowledged even though they are the daily experience of many service supporters.....they have been consigned to silence because of the dominance of service models that are geared toward problems and pathologies and the provision of care rather than models that emphasize peoples gifts and creating opportunities for them....we are not trained to celebrate people's capacities and it is past time that service supporters should begin to share such experiences with the wider community

- Often we are so –preoccupied with provision of high quality services that too little energy goes into supporting people to become known and valued in their local communities (Reinders 2002)
- If people are not actively valued then they will be certainly devalued
- ‘*Does he take sugar culture*’ ...people are not asked for their opinion

Power

The power people have to make things happen depends on three things

- Their personal resources compared to others including their competence, communication, money and friendships
- The degree to which they are dependent on others for assistance
- Whether alternative arrangements or relationships are available to them that reduces their dependency and offers real choices

The role of the supporter

- An expectation of growth and development in the person supported
- A commitment to good communication
- Taking your lead from the person
- No fault finding or blame
- A duty of care
- The recognition of boundaries

Basic attitudes of a supporter

- An understanding that their primary teachers are the people they support
- A willingness to grow in self knowledge
- The undertaking of self-development for sake of the development of others
- *'a supporter that fails to respond positively to people's relationships and community needs should not continue to be employed'*

Positive power

- Supporters must be open to learning the other person's world view and wishes and present their own in turn
- Positive use of power means offering oneself in service –using one's intelligence, gifts, and heart to help other people become who they are meant to be

Key question for supporters

- *If I were this person what would I be feeling that would cause me to act the way I do; what message would I be giving through my behaviour?*

Friendships and Intimacy

- One of the ignored roles that support staff must play in services is encouraging friendships for the people they support
- They should also consider that possibility that some people have no interest in having friends and must respect this
- In developing acquaintances supporters would encourage people to dress fashionably and look their best
- We must not impose our values and preferences on others we support

The need for go-betweens

- Facilitating conversation
- Finding joint activities for people to do
- When opportunity arises discreetly withdrawing
- Keeping in touch with both parties
- Checking how things are going
- Making discrete suggestions
- Subtly praising for how well they are getting on
- Using modern avenues e.g., internet chat rooms, singles clubs dating agencies etc whilst being aware of vulnerabilities.

Supporting acquaintances

- Home entertainment
- Mutual support
- Find opportunities for people to become supporters of others
- Recruiting befrienders

Cautions

- Matching of friends is often done by a professional worker
- Friendships may be artificial
- Motives of two parties can be very different
- 'lets create a new type of professional'
- Supporting friendships with members of the opposite sex...family, services are often wary

Barriers to Friendships

- Independent travel
- Lack of money
- The attitudes of people in the community
- Fears regarding sexual expression
- Positive identity/lack of self confidence
- Losing touch

Supporting intimate relationships

- Supporters may need to help the couple work through problems
- The couple may need help with negotiation skills
- Couple centred planning
- Supporting in making decisions about having children
- Specialist advice may need to be sought
- Supporters may need to be aware of their own limitations in this complex area
- Seek out help from other sources e.g., relationship counselling

Challenges and dilemmas

- Have the couple received sex education? Are they aware of contraceptives?
- Have they been taught to trust their own feelings?
- Are the couple able to give meaningful consent?
- Are the couple having a fling?
- Does the relationship offend your morals or those of other supporters?
- Could the relationship be abusive?
- Do individuals know who to talk to if bad things are happening?

For the service

- Paid supporters should know that they have responsibility to provide non-judgemental support for intimate relationships chosen by the people they support
- Clear guidelines are provided for supporters that deal with the previous questions
- Time is given at team meetings to discuss implementation of these guidelines
- Managers use one-to-one sessions to assist staff to work through issues of concern
- People in need of support are taught assertiveness and self-protection skills
- People have a circle of support
- Supporters are watchful for signs of difficulties of distress.

Last Words

- Relationships enrich our lives
- We need to look beyond service staff and family members in order to help people make friends
- This may take time and serious effort
- Will require ongoing support
- Will only be possible if built in trusted relationships

HOW?

- BRING PEOPLE TOGETHER
- JOIN COMMUNITY NETWORKS
- WORK IN PARTNERSHIP
- BALANCE RISK WITH OPPORTUNITY
- FIND FULFILLMENT

THE STARFISH STORY!

One day a woman was walking along the sea shore. She noticed that during the night thousands of starfish had washed up on the shore and they would surely die of the heat of the sun. She came upon a young boy who was methodically picking up a starfish and throwing it back into the surf. She said to him “there are thousands of starfish here-how can you possibly make a difference-let nature take its course”. The young boy reached down; picked up another starfish and sped it into the sea. Smiling, he turned to the woman and said:” I made a difference for that one!”

