

❖ Inclusive Futures ❖

Issue 3

"Everyone has a right to belong"

March 1999

Are you *★ Working with children or adults at risk of social exclusion or segregation. ★ Interested in developing your approach to inclusion ★ Seeking practical tools to strengthen the inclusion of vulnerable or challenging individuals into communities ★ Wanting contacts and links, or stronger networks of support for you or for your work...then read on!*

Welcome to the third newsletter from *Inclusive Futures*. Our aim is to share snippets of good news and hopeful information to help us all work for a more inclusive society. You can be part of this:

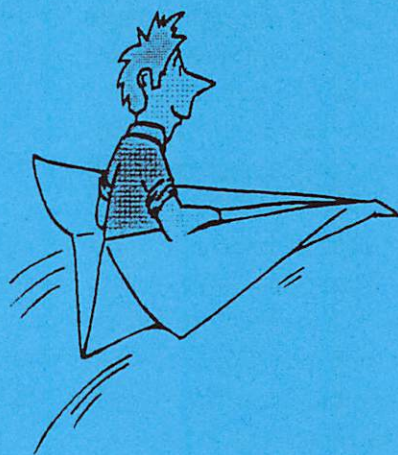
- ⇒ Send an item for issue 4 by 9th June - we are hungry for good news and stories from people who have got into inclusive communities. Issue 4 will be out by 9 July.
- ⇒ If you like this newsletter and wish to make a voluntary contribution towards the production and postage costs, then we would be very glad to receive it. Send a cheque made out to 'Inclusive Futures.'
- ⇒ Let us know about any mailing list amendments - such as your friends!
- ⇒ Photocopy this newsletter and pass copies to other people who would be interested.
- ⇒ Write to us at *Inclusive Futures*, 49 Northcliffe Avenue, Mapperley Nottingham, or email to batesmp@compuserve.com.
- ⇒ Support our conferences.

Conferences

During 1999 we hope that Jack Pearpoint and Marsha Forest will visit Nottingham again.

They are based at the Centre for Integrated Education and Community in Toronto, Canada. Jack and Marsha have worked with us in Nottingham each May since 1995, and many people are grateful for the inspiration and practical help that they have offered.

Conference and workshop dates are not confirmed at the time of going to press. Newsletter recipients will be sent full details of the 1999 events with Jack and Marsha as soon as these are available.



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Conferences

The Second International SRV conference, called "Creating Possibilities" will be held from 1st to 4th June 1999 in Boston Massachusetts.

Loads of exciting speakers from the US, Canada, Britain, Australia, New Zealand and Norway. Registration \$275 before 14 May, and onsite accommodation is cheap.

Details from Kathy Kennedy at email ktk@javanet.com or snail mail The Consortium, 187 High St, Suite 303, Holyoke, MA 01040 USA.

Healthy individuals and healthy communities

Is it possible to enjoy good health and yet be dislocated from your community? Dr. Malcolm Rigler is a GP in the West Midlands who answers an emphatic "No!" to this important question. Since the late 1970s he has been building a team around his GP surgery that share in the belief that community building, especially through art, is a vital way forward. Here are some of the initiatives that have been taken..

meet each other.

- A writer and poet was based at the Surgery for six months. He encouraged people to write about their experiences of sickness and health. These accounts lie in the waiting room for anyone to read, bringing comfort and a sense of community to others.

The pioneering work of Dr. Rigler's team is summed up by Professor Downie from the University of Glasgow:

"The central message is that disease and ill-health cannot be eradicated by narrowly medical means; they must be tackled in a community context."

Who are we if we don't heal ourselves and each other, teach ourselves and each other, love ourselves and each other, ask the crucial questions of ourselves and each other, or imagine for ourselves and each other?

David Hart

- schoolchildren have painted a mural in the waiting room.
- a craft workshop was established for isolated mothers to meet each other and create 'welcome baby' cards to send out from the Surgery to new mums.
- The Lantern Procession happens each March. People get together beforehand to make Chinese lanterns with the help of professional artists. The Procession is then led around their estate by a jazz band and ends with a party. Hundreds of local people join in and so unacquainted neighbours

"I work in the shopping Mall making lots of money. I ride around the third floor and get orders from the store people. Orders for the food court - burgers and coffee. I do it all myself.

I used to be in a programme making beads. I say "Bye! See you later!" Lifeworks started me in this new job. My case manager says I'm their best employee. I love it! I work four hours a day. I run around the Mall in my new red chair. I got lights and a mirror. I want a horn. I watch out for the babies.

I want something to do at night - like bowling or bingo - something to do out. If I could have anything in the whole wide world, I'd have a wheelchair van so I could go out anytime I want.

From a story told to Janice Faye Molnar at the Community Membership Project, Shriver Center, 200 Trapelo Road, Waltham, Massachusetts 02254.

Test your own IQ - *Inclusion Quotient*

Questions to ask about your organisation's policies and practices.

◆ How are staff encouraged to develop their knowledge and skills in inclusion? Is there support for

serve have at least four socially valued roles? These might be things like homeowner, community volunteer

◆ Does your organisation have a written statement affirming the value of community inclusion for the individuals it serves?

Inclusion means

Living, learning, working and enjoying leisure time with and among a majority of people who are not disabled

Physical presence and participation in the community that results in valued roles such as homeowner, tenant or neighbour, student, work colleague, customer, associate or friend

Providing appropriate supports that match the person's needs, strengths, interests and preferences rather than mere placement in integrated environments

or activist, employee, student, leisure participant, or friend.

◆ Has your organisation provided training on inclusion values, principles and practices in the past year to managers, staff, carers and volunteers?

study, promotion opportunities and so on?

◆ Where do service users spend most of their time? Are these places individualised, used by other members of the community, age appropriate, and highly valued by other community members?

◆ Is your organisation in touch with conferences and publications on community inclusion?

◆ Does every care plan include participation in community life?

Adapted from Toni Lippert's work for the Minnesota Governor's Planning Council on Developmental Disabilities

◆ Is there space in your building devoted to inclusion - such as library shelves and a notice board?

◆ Does each person you

Decision makers

The British Red Cross in Nottingham have set up a "Partnership Development Team". Their job is to link the community with some decision-makers in health and social services. Call Maggy Topley or Lawrence Quirk on 0115 988 1710 for more information.

A great internet website on inclusion. is at <http://www.quasar.ualberta.ca/ddc/incl/hope1.html>.

A Rosh Hashanah Birthday

Sally faces barriers. The barriers she faces are too often barriers that other people look at - and then run away from. She is in a wheelchair, and many never see the person after the wheels. The second barrier is the reason she is there ... she can't control her arms, legs, and head like others can.

The third barrier is the hardest of all for us who rely on words. She cannot talk.. She can mumble, she can sing, she can pray, but the words are not our words. But does she ever understand!

Sally knows what you are saying, what you mean. She understands people, for she observes, watches, and listens. She knows that life can be pure hell. She knows the world is not fair. But dignity is what she has: the dignity of a soul that has overcome despair, and overcomes it daily; the dignity of sense of humour that is humbling; the dignity of a curiosity that is forever on the prowl; and the dignity of a faith that literally holds her together.

Every single time that we arranged something for Jewish clients, Sally was the first one there. *My soul thirsts for God.* She revelled in the Oneg Shabbat service, the Hanukkah party, the Passover Seder. *Yea my heart is glad in him.*

And this evening, finally, was the first time she had ever been in a temple. Why not before? I had found myself unsure as we prepared. I knew she would love it, but would she be welcome? Would people stare at her, or at me? Who was I protecting?

Wait for the Lord, be strong, and let your heart take courage. When I finally got my courage together, and the gates of the temple seemed open, thanks to a caring rabbi, I finally told Sally we might be able to go to the Rosh Hashanah service.

Her response made my every foreseeable indignity seem so small. She jumped at my words. *I waited patiently for the Lord, he inclined to me, and heard my cry.* People often say that people like Sally will receive the rewards for their suffering in heaven. But for Sally life is now. The rabbi spoke that evening of being Jewish, of the

reality of belonging. *I believe that I shall see the goodness of the Lord in the land of the living.*

Now, at the end of the service, as the rabbi brought the Torah out, she helped Sally to touch and to feel. Differences in ages, nationalities, and abilities melted away in a moment when our journeys were truly one, bound together, as they always have been, by a single story: *I am the Lord your God, who brought you out of the land of Egypt,* by an ancient scroll: *My delight is in the law of the Lord,* and by a common song: *Let the people praise Thee. Let all the people praise Thee. Amen!*

Abridged for an article originally published in the Jewish Digest and the American Baptist by Bill Gaventa, the chaplain who had the privilege of being with Sally that Rosh Hashanah in Rochester, New York in 1980.

"In the earlier part of this century we believed that the new Behavioural Sciences, with a cunning scheme of rewards and punishments, would remove difficult behaviours effortlessly. I think that dream is dead. I hope so. I hope that we have come to a point in our history where we have started to recognise that: the end point of pure thought is probably death; that we are not going to think our way out of these problems; and that we require a new respect for the irrational, the intuitive, and the felt. We are discovering that we need people who step out of the mould of what we created....to remind us who we are and who we need to be for one and other".

Herb Lovett 1995

Nottingham City's Inclusive Education Policy Statement

Nottingham City Education Committee... believes that all children can learn and that including all children with disabilities or special educational needs in their local school is a major contributor to tackling discrimination...

The Committee therefore believes that it is essential to continue to reduce the number of children in special schools....

Much of the practice within the City's special schools is excellent and the Committee will continue to maintain a range of special provision in order to preserve a range of choice for parents.

At the same time, continuing to develop the role of special schools will allow the re-direction of their expertise and resources into mainstream schools. This will provide additional support to mainstream school staff to enable them to continue to develop effective inclusion for children with disabilities and will improve provision for all children.

This policy will continue to fulfil the right of pupils without disabilities or other difficulties to experience the fullness of human diversity.

The Education Committee endorses the target that by the year 2002 every child with special educational needs will be able to attend a mainstream school in Nottingham, if they and their parents wish to.

The number of pupils expelled from secondary schools in the Nottinghamshire fell from 191 in 1997 to 169 in 1998. Work undertaken in the last two years includes:

- schools successfully working together to promote good behaviour
- a Behaviour Support Plan produced by the county council
- training to support teachers and schools
- a series of conferences in the summer term to share best practice.

"If the community is not functioning properly, then the people don't function properly... it may not sound much, but to make someone smile and forge a few friendships is better than any medicine"

Lynda Lawley, nurse practitioner with Dr Malcolm Rigler

"Relationships will evolve out of common interests... Free-forming friendships help to ensure that there is a reciprocal component to the friendships"

Anyone for a beer?

8pm onwards on
10th June and
28 October
1999 at the
Gateway Hotel,
Nottingham (tel
0115 979 4949).

Ask at
Reception for
the Inclusive
Futures group.
Everyone is
welcome to
meet and talk
about the
realities of
inclusion.

Are you studying inclusion, perhaps for an essay? Email to batesmp@compuserve.com for a list of 450 academic references on the subject. If you need a paper version, you will need to send an A4 stamped addressed envelope and a cheque for £2 to Peter Bates, 96 Burlington Road, Sherwood, Nottingham NG5 2GS.

Toronto Summer Institute on Community Integration July 1998

Workshop with John McKnight

For the past forty years, John McKnight has studied successful community building initiatives in hundreds of neighbourhoods across North America. John is Director, Community Studies Program at the Centre for Urban Affairs and Policy Research at Northwestern University, Illinois.

This work has led him to a set of very radical conclusions about what works in building healthy and inclusive communities.

A key idea behind John McKnight's work is that communities cannot be rebuilt by focusing on their needs, problems and deficiencies. Rather, community building starts with the process of locating the assets, skills and capacities of residents, citizens' associations and local institutions.

John McKnight's contention is that modern service systems act in ways that disable their clients (these 'clients' may be people labelled disabled, older people, 'sink' schools, failing communities or whatever can be deemed to have a need of some sort) by focusing on the 'half empty' description and attempting to remedy this in some way.

Service systems will never do a good job of building community, in fact they will damage it. If you want excluded people to be introduced into community or the disaffected to regain their 'affection', then the only people to do this are community people. Residents of group homes for the disabled are introduced in this approach as 'strangers in our midst' as far as the community is concerned and the natural hospitality of communities is therefore mobilised. I found the following two quotes from John deeply challenging.

"You must never let the community inviters think they are doing something that human services could be doing..

..Never let them see the group home, it is your enemy, the community will see the residents as 'them'.

If a neighbourhood group wants to do something about tidying up their streets, they "don't want John's 'bad heart' they want to borrow his

rake" - i.e. gifts not deficits. Much of John McKnight's work is now focused on the practicalities of community building and in particular creating community connections for individuals who have been labelled in some way.

Further details of the work of the Institute can be found on their website at;

<http://www.nwu.edu/IPR/abcd.html>.

This was written by Derek Wilson, Educational Psychologist, working in Nottingham.

Much of the workshop was spent clarifying the ways in which the values and procedures of formal service systems differ from those we expect from typical community life. Here are some of the key dimensions....

FORMAL SYSTEMS ASSOCIATIONAL COMMUNITY

Control	Consent
Expertise	Experience
Fixes	Fulfils
Official language	Vernacular
Objectivity ('the study')	Subjective ('the story')
Doing (and goals)	Being (is enough in itself)
Imperial	homely
Participation required	Voluntary
Lots of the same thing	Diversity and Difference
Measured tread of change	Quickness of response
Person Anonymous	Personal
Order	Hidden order
Impartial	Partisan
Analysis	Synthesis
Destination	Journey
Written information	Oral and memories
Rules	'Habits of the heart'
Repetitive	Creative
Money	'Gifts'
Reasonable and defensible	Goes to unreasonable lengths
Safety (risk management)	Risks taken
Tragedy not processed	Where tragedy happens and there are people who know how to deal with it
Deals with the measurable	Things are 'valued'
Procedures	Rituals e.g. funerals
Professional 'distance'	You come as yourself

Employment page

Real Jobs

Malcolm Bass and Robert Drewett interviewed 22 people who had all started work through job coaching in Liverpool. They compared life in the day centre, before starting the job, with life at work. Two of the things that they looked at were engagement and interaction.

Engagement occurs when the focus person is active, doing something, engaging with a task, rather than passive. The people they studied spent more time engaged on tasks when they were at work, compared with the day centre.

Interaction occurs when the focus person exchanges a greeting, receives an instruction, or participates in a conversation with co-workers or staff. In the day centre, clients with the highest level of need had the smallest amount of interaction with staff. This was put right in the employment setting, where job coaches matched the amount of help they gave to the support needs of the individual. Overall, they spent the same total amount of time with the group.

The amount of interaction with non-staff, non-disabled people was almost nil in the day centre and increased substantially, especially for the people with the smallest support needs.

Aiming High!

Congratulations to North Birmingham Mental Health NHS Trust, who have set themselves an ambitious target. Here are some extracts from their "Employment and Training Service Values". They say that people with mental health problems have a right:

- ⇒ to make a contribution to the economy through paid employment.
- ⇒ to receive advice, education, and training in settings which strive to avoid stigmatisation by the community, or segregation from the wider community.
- ⇒ to work in open employment settings, taking account of longer term needs, and with employers who can understand and accommodate flexible working patterns.
- ⇒ to be employed in valued work, in conditions which do not exploit them - i.e. offer realistic reward for work done.

We wish everyone in the Trust and its partners well in their endeavours to 'walk the talk'.

**Tell me and I will forget.
Show me and I may
remember.
Include me,
and I will understand.**

...and internationally....

The World Association for Supported Employment (WASE) is working with the International Association for the Scientific Study of Intellectual Disabilities (IASSID). Their focus is developing criteria for supported life, and criteria for supported employment is one strand of this work. Results will be presented at the WASE conference in Rome in March 1999, and the IASSID Congress in Seattle in August 2000. For more information contact Michael Kamp, secretary general of WASE, Steenpad 3, 4797 SG Willemstad, The Netherlands. Email: ckamp@xs4all.nl

In 1 June 1997, Texas started a five year programme. Their aim is to develop 20 local demonstration sites so that more people with severe learning disabilities can work in ordinary jobs. Some demonstration sites will show how to convert from sheltered employment to community integrated employment. This will include building local coalitions, redirecting funding to support integrated work, and increasing employer awareness. For more information, contact Norine Jaloway, Executive Director, Imagine Enterprises at njaloway@eden.com

Productive in His Own Way

Productive members of society - this is what most education, training and employment programs for disabled people are intended to create. It is a good and noble purpose that has, quite literally, opened doors for many. Whatever good it may bring, however, this utilitarian approach could be fatally flawed if crudely applied to the medical care of all disabled people. It would tolerate, perhaps even condone, the death of my son.

Aidan is severely disabled, the result of a rare combination of brain abnormalities. Now 6 years old, he is more like an infant: he cannot hold his head upright; he cannot crawl, walk or talk. The seizures that fire through his brain have proved incurable after a dozen or more medications. He is profoundly mentally retarded. We feed him through a tube that runs directly into his small intestine, to avoid aspiration pneumonia. The visual world is, for him, a dim play of shadows.

It would seem, then, that Aidan is not and will never be a "productive member of society." Insurance companies are especially frustrated by Aidan's lack of productivity. His care is expensive, with many hospital stays, regular visits to various doctors and more than \$1,000 in food bills a month.

Once, when a nurse friend of ours was arguing to an agent of a health maintenance organization that she should continue her visits to Aidan, the agent complained that it was the parents' fault, all of

this expense, for "keeping these kids alive." Care for Aidan, the agent implied, was socially irresponsible because it took resources away from other, more promising and profitable uses. These agents press at us constantly, saying that the formula specially made to suit his tube-feeding is not "medically necessary," and therefore not covered. Or they balk at authorizing a referral to yet another specialist. They think that Aidan's limited prospects are just not worth the work and anguish.

But Aidan is worth it. His value comes precisely from the challenge he poses to the usual definitions of "value." He is a living reminder that the range of human experience is broader than the narrow confines of balance sheets and business plans. While he will never pay back society in financial terms, he certainly gives to those around him.

To my wife and me he has given the gift of perspective. A good day now is not a matter of more income or greater social status or new things from the mall, but a time of fewer seizures or his comfortable sleep in his own bed. He has expanded the world of his little sister, Margaret. Though only 4, she is not afraid of wheelchairs or white canes; she knows that not everyone walks or talks or sees.

He has a similar impact on his friends at school - yes, he is

entitled by law to be included in the local public school. His classmates were put off at first by the wheelchair, the seizures, the strangeness. But after a simple explanation - "he was just born that way" - they come to accept him, even compete to push his chair or hold his hand. Some have forged real friendships with him, asking to trick-or-treat with him at Halloween or inviting him to a birthday party.

His most profound effect, however, is the reflection he inspires in many who meet him. Without a word, he poses the deepest questions. What is a life? What makes any life, even one so limited, worth it? Strangers have come up on crowded streets, touching his shoulder or tousling his hair, giving us their abbreviated answers. Usually they say something about love or grace, something well beyond the material concerns of everyday life.

With Aidan, it's never about productivity, it is about humanity."

GEORGE T. CRANE

George T. Crane teaches political science at Williams College in Williamstown, Massachusetts. This was originally published in the New York Times.