# PRESENCE IS NOT ENOUGH:

SUSTAINING GOOD LIVES
OVER THE LONG TERM

### And never forget:

Stay A Lover Of Little Things, Above All Else.

Prayers. Pearls. Compliments. Movie Nights. Letters From Home...home.

And Those Who Believed In You First.

• • •

## FOCUS ON PRINCIPLES OVER POLICY

## Core Principles

- Each person is unique and different
- □ Choose Community
- Focus on Relationship always
- Start with the Gifts and Contributions of the person
- Shared Decision-making
- Aim for an ordinary, good life through Valued
   Social Roles and standards
- Lifelong Learning Growing high expectations
- Gather with others to do the work

## Principles in action mean...

- never 24 hour paid support
- □ all support is 1:1
- no support for segregated activities
- a Supporter only works for one family
- co-op member <u>not</u> paid to support
- always start with interest and contribution
- individual is involved in hiring

## These principles...

- Guide along one path rather than another
   THIS WAY
- Give direction in times of choice and dilemma THIS WAY IS BETTER
- Tell us what to avoid
  IF YOU WANT THIS KIND OF LIFE, THEN...
- Remind us that this matters because people are vulnerable
   THIS MATTERS

### KEEP EXPECTATIONS HIGH

## High Expectations

- Avoid "good enough"
- Avoid "better than many others"
- □ Have a clear Vision early on
- Keep valued age peers in your community as your measuring stick

## TAKE YOUR TIME

## See things over longer periods of time

- Real life takes place over weeks, months and even years – rather than hours, days and weeks
  - Think in real time intervals and not in service goals and objectives
- The building of genuine relationship often takes place over long periods of time
  - Many roles may be enjoyed before friendship
- □ Life defining roles unfold over a lifetime

### CHANGE HAPPENS - CHRONICALLY

## Life is ever-changing

- □ Be prepared to always start over
- Every start is from the beginning
  - This can be exhausting if unexpected
- Reasons are varied:
  - Related to the person
  - Related to the other people in his environment
  - Related to the environment
- Accept and embrace flow and change

## FAMILIES SUPPORTING FAMILIES IS A POWERFUL DYNAMIC

## Family Group Support is a model to sustain a good life over time

- Safeguards are important
  - Families share common visions but do not live in each other's pockets
  - Individual lives are kept separate, unique
  - A range of ages is ideal
  - A long term succession plan is essential
- A shared coordinator is cost efficient, supportive of common principles, and a satisfying work role for the long term

## HOME, ROLES AND RELATIONSHIPS ARE ESSENTIAL - ALWAYS

## These things are always important

- □ Home
- □ Roles (with contribution)
- Relationships

All of these need attention all of the time

## HOME

## Home is made every single day

- The work of making home begins again every single day
  - In small ways
- This is the place where the person gets to be the "king of their castle"
- □ Not CHOICES, but GOVERNING and DIRECTION
  - The rhythms of the day
  - The social atmosphere of the home
  - Who comes and goes
  - Objects chosen and sent away

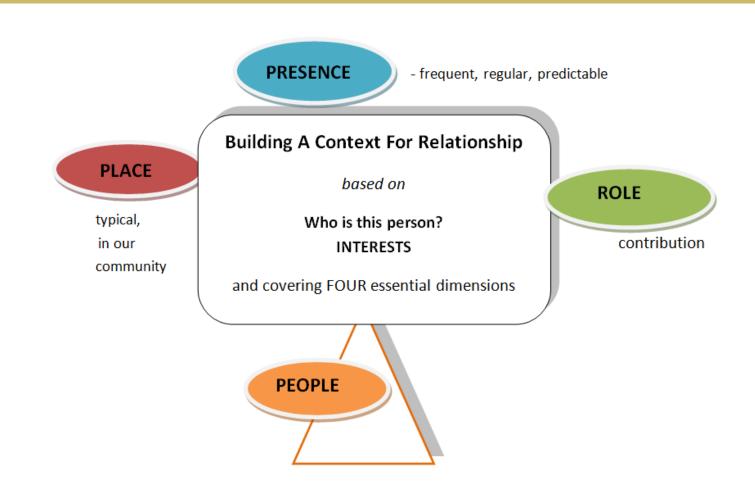
# A RELENTLESS FOCUS ON RELATIONSHIP

#### A focus on relationship brings about:

- □ Identity (Roles)
- Purpose (Roles, Contribution)
- □ Focus on use of paid supports
- □ Places of Belonging

- Brings richness and focus
- Affords an essential safeguard

## Building a Context for Relationship (BCR)



#### You cannot create RELATIONSHIP...

...but you can recognize, encourage, and design opportunities in which the miracle of friendship is more likely to occur.

#### A CONTEXT FOR RELATIONSHIP

- discovering community spaces
- ensuring presence
- designing and supporting valued roles
- connecting with other people

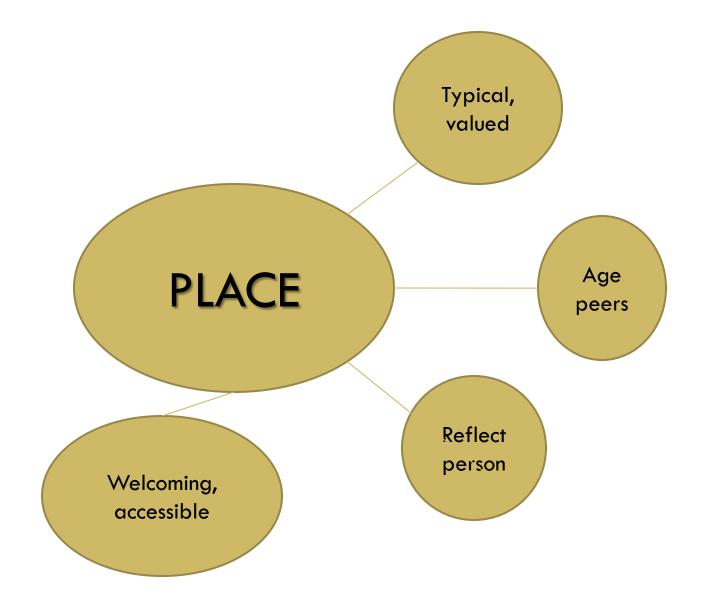
Interests/Passions
Skills

Likes/
Dislikes

Personality

WHO IS THIS PERSON?





So, spending time apart in special classes day programmes segregated recreation group homes do not count if your goal is valued, freely-given

## **RELATIONSHIP**

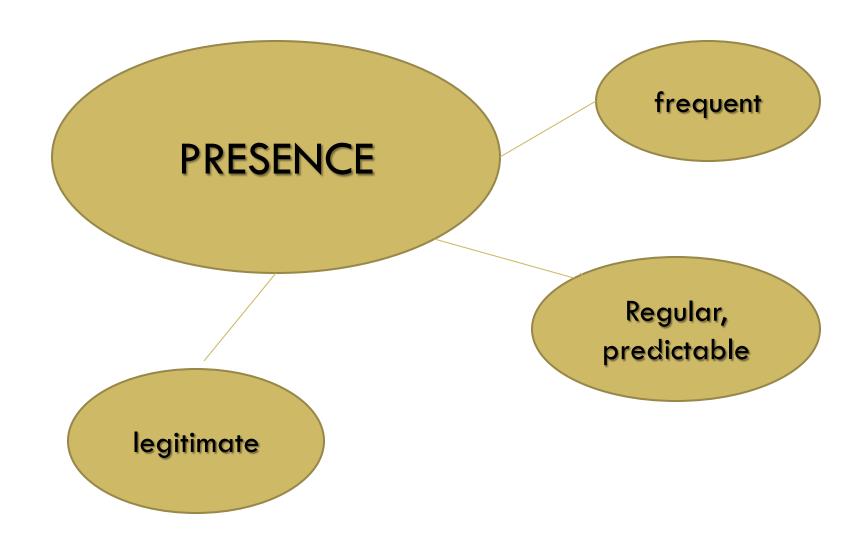


## If people are not present...

- \* frequently
- \* predictably
- \* legitimately

## Then NOTHING will happen

(except by chance)

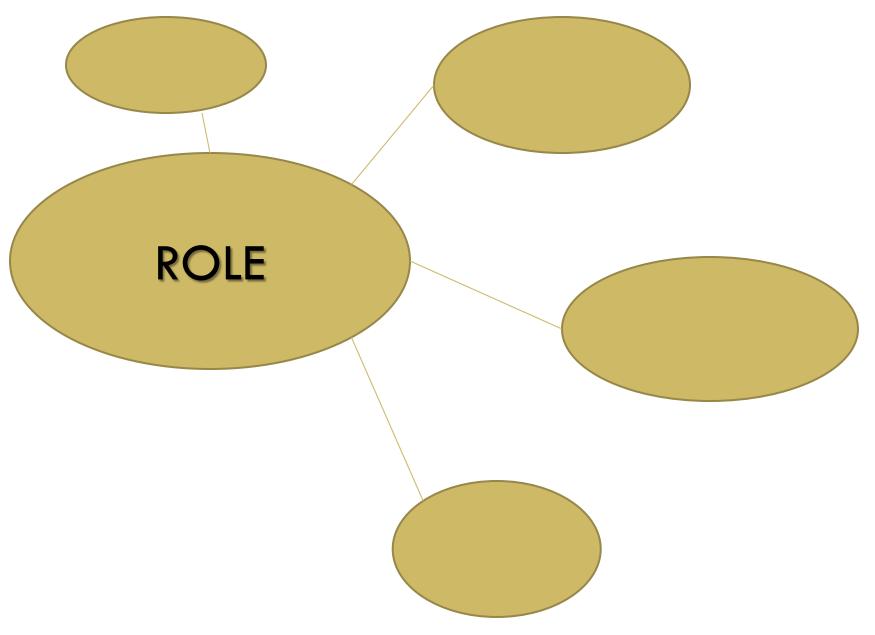


So...

spontaneous one-offs, irregular attendance, constant variety

do not count if your goal is

RELATIONSHIP



c 2004, 2009, 2011, 2013 Janet Klees janet@legacies.ca

#### Roles versus Activities

#### She likes...

- Gardening
- Walking
- Reading
- Going to church



#### She is a...

- Vegetable gardener
- Walking club member
- Book club member
- Altar guild member





#### Activities related to this role

- > joining a local community garden
- working in own garden
- buying gardening supplies
- visiting a flower exhibit
- entering a local garden show
- joining a gardening club
- > volunteering to garden at co-op
- > subscribe to gardening magazine
- send away for stuff (seeds, tools)
- > design garden on computer

- exchange plant cuttings or produce with others
- donate flowers or produce
- plant a balcony garden
- experiment with an indoor herb garden
- ask others about their gardens
- can your own produce, make salsa,bake a pie
- visit and support a rooftop garden
- help a neighbour in the garden
- plant heritage seeds

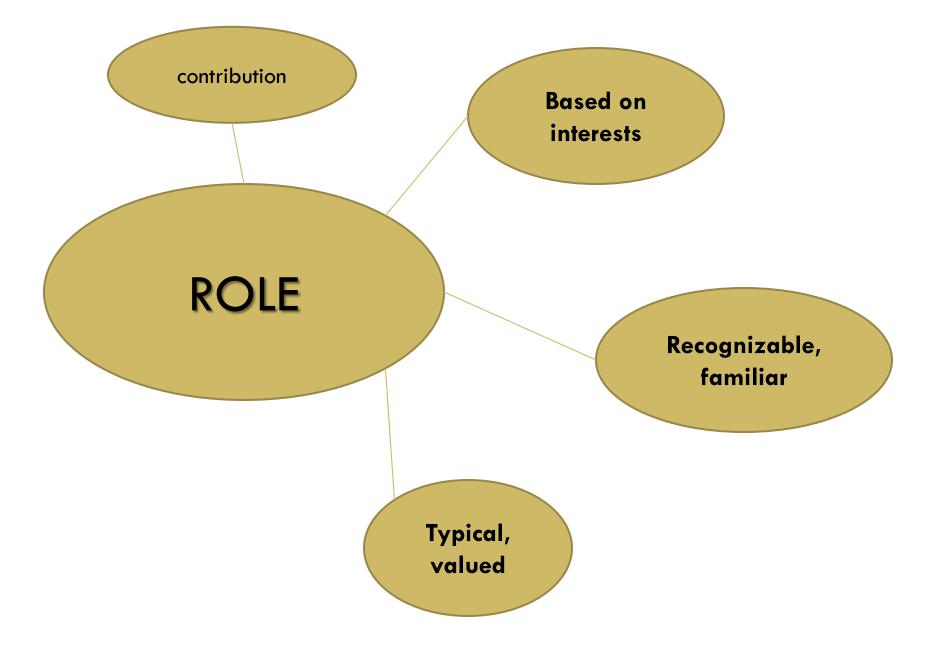
## Tiffany paints

Mon	Tues	Wed	Thurs	Fri	Sat	Sun
	Painting lesson					

## Tiffany is an artist

Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Check on sales at shop	Buy art supplies	New shop to sell art?	Choose frames for art	Art studio	Reading art guild newsletter	
				Art studio	Show new art to friend at lunch	
Local painting exhibit	Painting at home			Plan new art shows		
		Art Guild mtg	Sign new art			

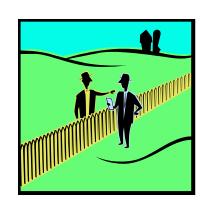
# At the heart ROLE CONTRIBUTION



### Big "little" Roles







**Friend** 

c 2004, 20





So...

movies,
mall walking,



going for long drives,

relaxing alone at home



do not count if your goal is

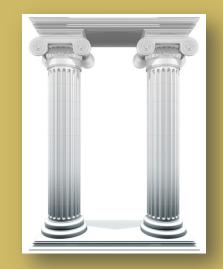


## RELATIONSHIP

#### If things are not working out...

...then,

one of the four pillars
of the
context for relationship







### Role Tips

- □ Pick one familiar role
- □ Pick one family role
- □ Pick a role based on Interests
- □ Layer Roles over time
- At the heart of role is Contribution
- □ Presence is not enough avoid observer status

### **Relationship Tips**

- Stop counting whose turn
- Make reciprocal easy
- ☐ Ask for small things
- Ensure that the support person is the BRIDGE to relationships and not the friend or relationship itself
- Be creative in solving the "loneliness" question

### To sustain good lives over the long term

- Principles
- □ Vision
- High Expectations
- □ Take Time
- Change Happens continually
- Families Supporting Families
- □ Focus on Home
- Focus on Relationships
- Celebrate everything
- See the small things