

A person wearing blue jeans and a dark jacket is standing on a paved surface, possibly a parking lot or a road. The person is positioned at the top center of the frame. A large, semi-transparent white arrow points downwards from the person's feet towards the bottom of the image. The background is a grey, textured pavement with white lines. An orange rectangular box is overlaid on the lower half of the image, containing white text.

**Circles of Support:
what they are,
what they look like,
the impact they have**

EXERCISE

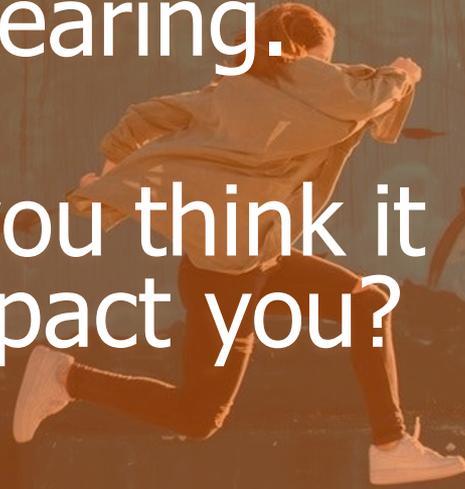
My Circle of Support



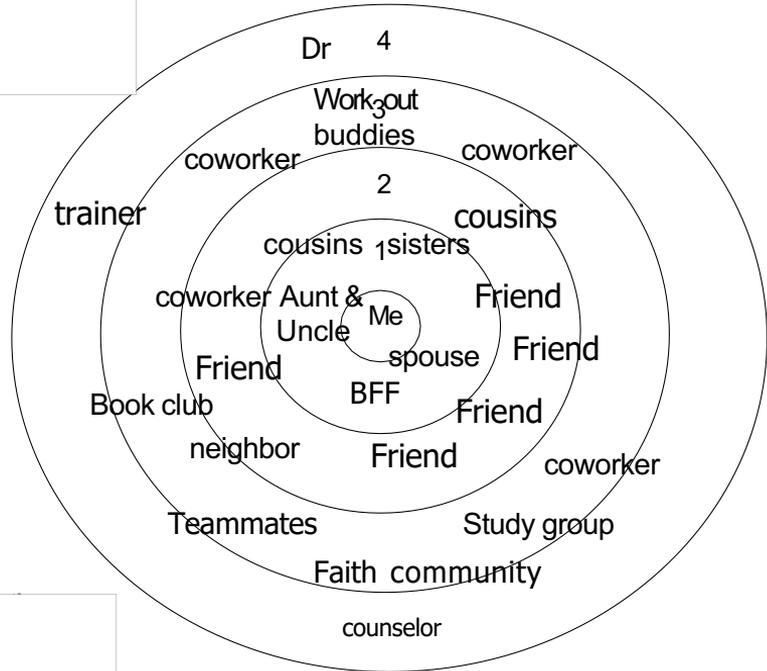
EXERCISE

Imagine your Circle
disappearing.

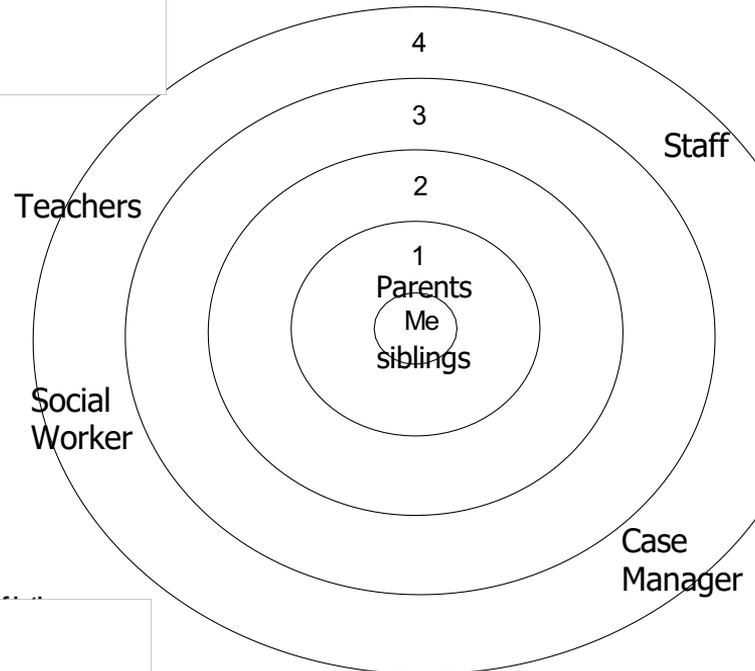
How do you think it
might impact you?



You and I



People with Disabilities



"Loneliness is the newest health crisis in our country"

News
FLASH!

**Disability & the Constant Threat of Isolation
Accountability—How you may Knowingly & Unknowingly
Contributing to the Exclusion & Isolation of Disabled People.**

THE TOLL ISOLATION TAKES ON THE BODY

Human beings are by nature social animals and studies now show that **regular social activity and engagement does wonders for our health**. But the opposite is also true — a deep sense of isolation can affect the body adversely over time...

- **Deteriorates physical health** – Weakens immune system, impairs sleep, contributes to heart disease and premature death.
- **Erodes self-confidence** – Development of social anxiety over a prolonged period of non-interaction with other people.
- **Produces mental problems** – Greater risk for dementia and psychosomatic illnesses.

**Disabled people are a diverse group –
but loneliness is a common
experience**

By [Laura Oakley](#) · Jul 11, 2017

As A Disabled Person I Experience Loneliness Every Day

11/07/2017 05:24 BST | Updated 11/07/2017 07:55 BST

Why should we be concerned?

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Earliest Circles: created by our caregivers; playdates, lessons, parties

Earliest Decisionmakers: establish themselves within their Circles as leaders or followers

Middle School: independent thinking manifests, in the context of huge social demands and expectations of belonging and conforming to the group. Social anxieties, pressures and other challenges become complex. Anyone who is different is not celebrated; they are isolated. Circles begin to grow for some, shrink for others.

Adulthood: maturity (through age) brings appreciation for differences or the holding on of pre-conceived notions. We have our own children, and begin to think about how we will model those beliefs we hope our children will embrace. We have established our own Circles that represent who ***we choose to spend our lives with.***

People without disabilities



People with disabilities



Earliest Circles: created by our caregivers; playdates, lessons, parties

Earliest Decisionmakers: establish themselves within their Circles as leaders or followers. Children with disabilities and their peers are just beginning to see differences, but they don't assign stigmas or reduced value.

Middle School: independent thinking manifests, in the context of huge social demands and expectations of belonging and conforming to the group. Social anxieties, pressures and other challenges become complex. Anyone who is different is not celebrated; they are isolated. Circles begin to grow for some, shrink for others.

Adulthood: people with disabilities have grown in isolation, are lonely, dependent on caregivers who are paid to be in their lives. Family members become decision makers, shifting those relationships. They may be known in their communities, but they are not included.

Addressing the barriers to building Circles of Support

The internal struggles for families:

“I don’t want to bother people”
“I’m embarrassed to ask for help”
“I should be able to do this alone”
“What will they think of me?”
“If I ask them to help, they might not want to”

The external struggles for communities:

“We want to help, but don’t know how”
“We might sound politically incorrect”
“We can’t afford to take this on”
“We don’t have the skills or knowledge”
“I don’t know who to ask”

Societal presumptions:

“Since they’re disabled, they don’t really have anything of value to contribute. They just need care.”
“They must have family and friends who love them.”
“Systems are doing a good job of taking care of their needs and quality of life.”

When we first meet someone new:

How do we learn
about a person?
What do we ask?



People with disabilities often don't get to
Introduce themselves.

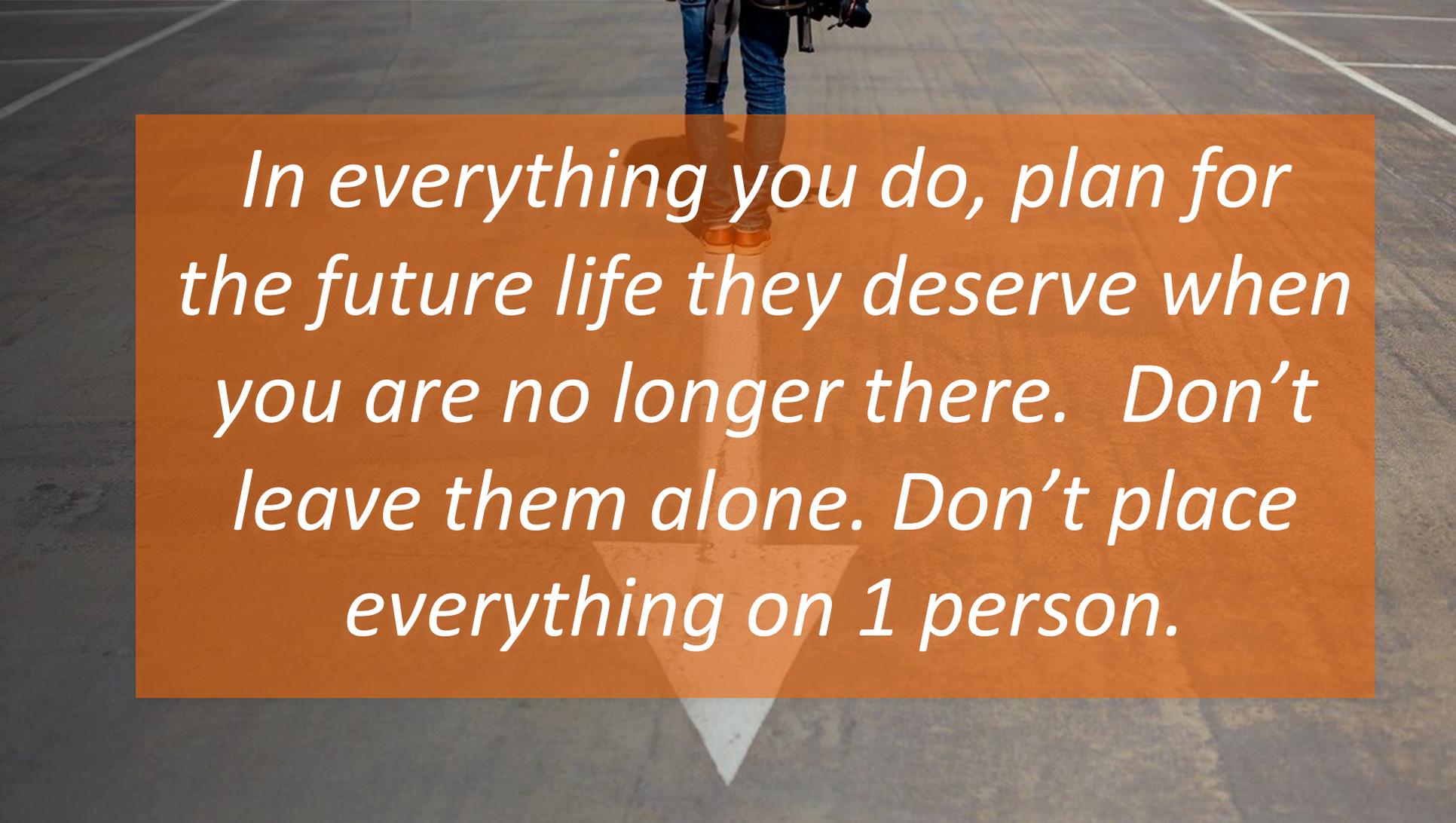
The first things we may see or hear:

- *The disability and/or the diagnosis*
- *Description of their anticipated behaviors*
- *Their limitations – what they can't do*
- *No introduction at all as they stand there*

SHIFTING OUR PERSPECTIVE

A close-up photograph of a person's hand, with the index finger pointing to the right. The hand is positioned on the left side of the frame. An orange rectangular overlay is placed over the right side of the hand and extends towards the right edge of the image. Inside this orange rectangle, there is white text. The background is a solid, dark blue-grey color.

*Rethinking our
Roles as
parents and
loved ones*

A person wearing blue jeans and brown boots stands on a paved surface. A large white arrow points downwards from the person's feet. The background is a grey asphalt or concrete surface with white lines. An orange semi-transparent rectangle is overlaid on the image, containing white text.

In everything you do, plan for the future life they deserve when you are no longer there. Don't leave them alone. Don't place everything on 1 person.

Your “new” job

- *Begin thinking about who is in your child’s life.*
- *Gather them together a few times per year. Tell them about how your child is doing. Tell them what your child loves, where they would love to go or what they would love to do. Ask if anyone is willing to come and spend time, or help you with other kids, or research new opportunities for you.*
- *If they have no one, start looking. Continue looking, all the time. Ask who is in their programs, call on old teachers, aides, support staff.*
- *See the “Where are you, my friend” document.*



Document available on
CherylRyanChan.com

Where are you, my friend?



Finding new relationships to add to our Circle

Places and Spaces:

1. Social Media

- a. FaceTime & Skype are great ways to set up regular connections with family members who live far away.
- b. Friendship matching app: Making Authentic Friends
www.makingauthenticfriendships.com. Created by a sibling.
- c. Addressing safety: co-management of accounts, appropriate check-ins, agree on respectful boundaries.

We MUST REMEMBER that social media is the way that people communicate in the age we live in. Denying our citizens access if they want it because of our own fears is wrong, simply stated.

2. Volunteering & Networking

- a. You: get involved in local resource centers, groups, related events and activities. Meet people, invite for coffee those you connect with. Develop relationships. Always have an eye toward building the Circle. Listen for relatable lifestyles, interests, values.
- b. Your loved one: be person-centered – what do they love, and how creative can you get in finding things that speak to that? Think about Andy and the lesson: "It wasn't my job to BE his friend."

3. Creating intentional opportunities

- a. Contact your loved one's program teams. Ask: who are the friends, OR are there any peers my person seems to connect with? Draft an email inviting the family to connect. Send it to the program or team chair, and ask them to forward it. This gets around HIPAA.

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- b. Book a birthday party at a fun venue, but don't make it a birthday thing.
- c. Print business cards or postcards for direct care staff (see sample).

4. Getting ready to make friends and recruiting Circle members to help

- a. Social skills are critical, for every level of ability. Practicing in safe spaces with trusted people first, who can correct lovingly, is a great way to learn. A great resource for finding skill building exercises is at do2learn.com.

It's also a great Circle task for someone to take on. The exercises on this site do not require any particular professional skill set or experience. Ask 1 or 2 people your person likes, to think about spending 1 hour a week or 1 Saturday a month working on social skill exercises.

These can be done at your home or the Circle members. In general, the more varied environments a citizen can be exposed to and practice in, where they are safe and can have guided practice, the better.

Circle members can increase their demands for appropriate communication and behavior during naturally occurring time together. Talk to everyone about the expectations and coaching you are doing for your citizen. Get everyone on the same page.

Other Tools to use

- Letter of Intent: a manual that contains all the important information about your loved one.

<https://info.specialneedsplanning.com/download-a-sample-letter-of-intent>

- Profile Book: a simplified picture of your loved one, what they like and dislike, what kind of person they connect with, what is important to them, how to communicate with them.

https://drive.google.com/file/d/12cRwxI8NSZJOOHWvU9o-NSbN_DPAvTa-/view?usp=sharing

- [Person-Centered Plan](#)

Email: cherylryanchan@gmail.com



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*A Circle of Support is the last,
most important gift we can give
the person we love.*

THANK YOU



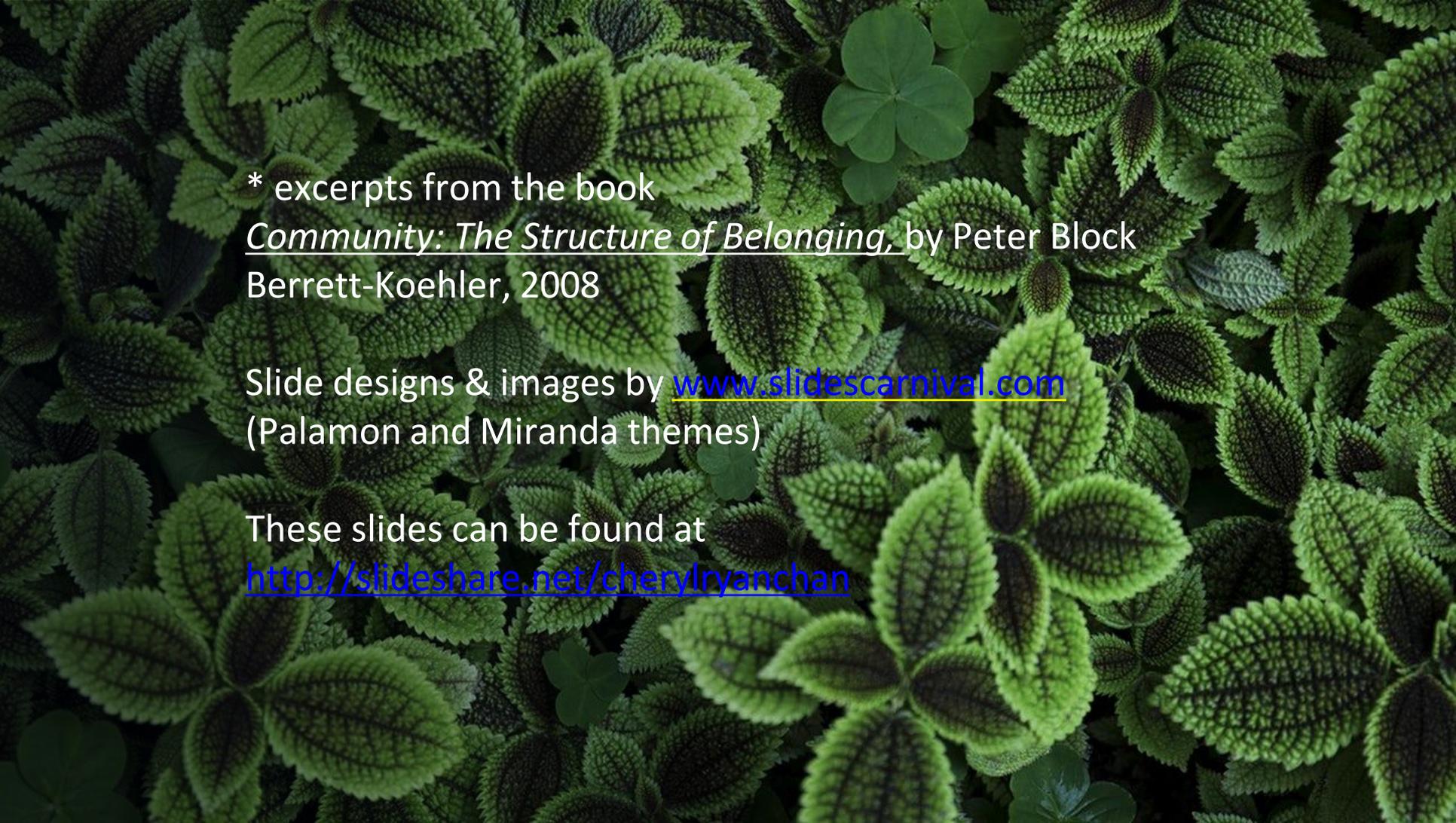
It is up to every one of us to steward the humanity of those who are considered less. Failure to do so is a failure of humanity in general.

Circles of Support are a natural element of our existence. Without them, we cannot survive; as a race, as a community, or as individuals.

Hold the space for the voices left unheard.

Cheryl

CherylRyanChan.com



* excerpts from the book
Community: The Structure of Belonging, by Peter Block
Berrett-Koehler, 2008

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These slides can be found at
<http://slideshare.net/cherlyryanchan>