

SELF-DIRECTION: KEEPING IT REAL

2015 Self-Determination Conference

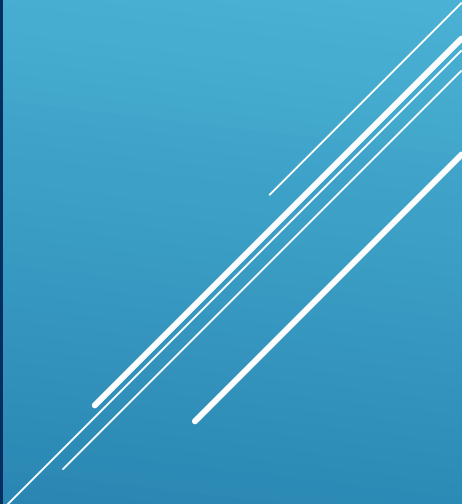
Sometimes I just want
someone to hug me and say,
“I know it’s hard. You’re going
to be okay. Here is chocolate
and 6 million dollars.”



**We are members of the Save IRIS Steering Committee & the team leading
Save IRIS: Wisconsin's Self-Direction Advocates**



Goals for today:

- Understand what self-direction currently looks like in long-term care (LTC) in Wisconsin.
 - Learn about “Family Care/IRIS 2.0”- what we know & what we don’t know.
 - Define what we want self-direction to look like in the new system & advocacy steps we can take.
 - Learn practical steps on how to live a self-directed life.
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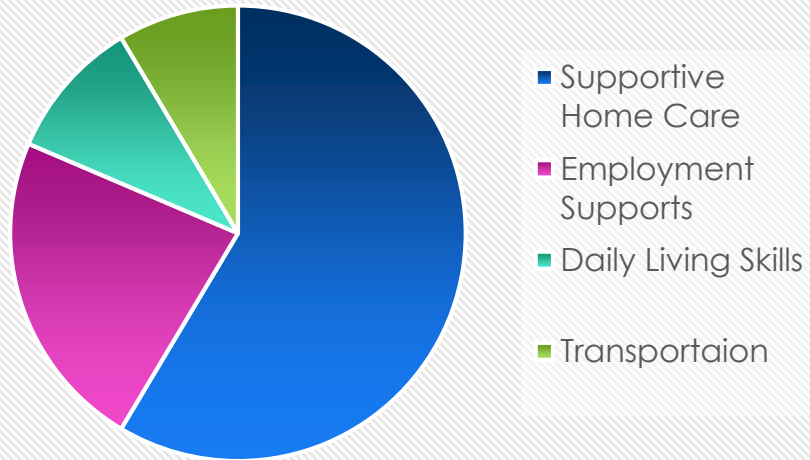
Key Ideas for Full Self-Direction in Long-Term Care



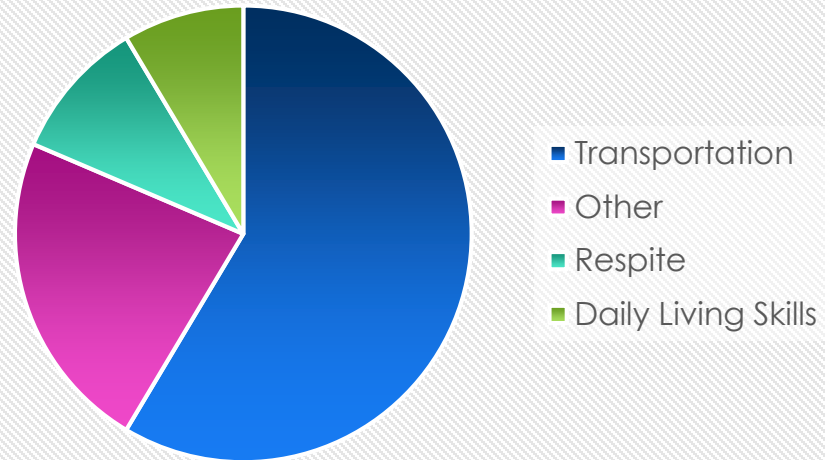
BUDGET AUTHORITY

- ▶ *Decision-making authority over how the Medicaid funding in your individual budget is spent*

Long-Term Care Budget For Charlie



Long-Term Care Budget for Ella



EMPLOYER AUTHORITY

- ▶ *Decision-making authority regarding who provides your services & how the services are provided. You get to recruit, hire, train, supervise, & fire the people who provide your services, including parents, spouses, & relatives.*



You're hired!

SUPPORT

- ▶ *Participants who self-direct need to have access to ongoing support when they need it.*
- ▶ *Currently IRIS consultants and fiscal agents provide this support.*



Family Care

- ▶ Partial Budget Authority over some services on the plan & over funds within those service areas.
- ▶ A team of a Care Manager & an RN oversee the participant's support plan & authorize services.
- ▶ Restricted list of providers in the Managed Care Organization's provider network.
- ▶ Partial Self-Direction

IRIS

- ▶ Full Budget Authority over whole LTC plan & all funds allocated.
- ▶ An IRIS Consultant provides support, but the participant authorizes the services on the plan.
- ▶ The participant can hire who she wants.
- ▶ Self-Directs ALL services.

SELF-DIRECTION IS DIFFERENT IN FAMILY CARE & IRIS

What do we want DHS to include in the Family Care/IRIS 2.0 waiver?

Full
Employer
Authority

Full Budget
Authority

Ability to
set one's
own goals

Adequate
Support for
self-
direction

A robust
system for
the
resolution
of
grievances

The
opportunity
for
everyone
to elect to
self-direct

WE MUST CONTINUE
TO ADVOCATE FOR
WHAT WORKS WELL IN
LONG-TERM CARE



The “Family Care/IRIS 2.0” Time Line

Fall 2015: DHS held public hearings & they accepted comments until October 30th.

January- March 2016: DHS drafts their concept plan.

April 1, 2016: DHS submits their concept plan to the Legislature.

Upon Legislative Approval: DHS drafts waiver request.

July 1, 2016: DHS releases waiver for public comment.

September 30, 2016: DHS submits waiver to the federal government (CMS).

January 2017 or at a later date set by DHS: Implement Family Care/IRIS 2.0 statewide. (Waiver has to be approved by CMS prior to implementation.)

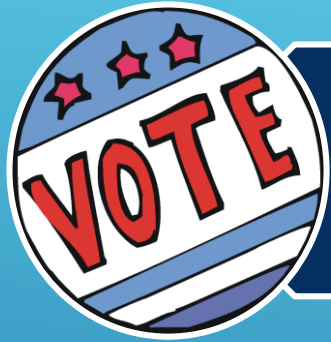


Wisconsin will be moving toward a model using IHA's (Integrated Health Agencies).

Self-Direction will no longer have a separate program.

We need to stay engaged, collaborate, & advocate.

HOW DO WE STAY INVOLVED IN ADVOCACY?



Vote



Stay informed



Know your legislators

Helpful links:

<https://www.facebook.com/save.iris.wi/>

<http://legis.wisconsin.gov/>

<http://www.incontrolwisconsin.org/resources/changes-to-wi-long-term-care/>

<http://www.saveiris.org/>

<http://www.wilongtermcarecoalition.org/>

Save IRIS: Wisconsin's Self-Direction Advocates will...

- ❖ Educate long-term care participants about the status of self-direction in the new long-term care model, support them with advocacy efforts, & provide guidance regarding communicating effectively with insurance companies.
- ❖ Advocate for a strong self-direction option in the new Medicaid waiver that will closely mirror IRIS.
- ❖ Serve on decision-making groups with IHA representatives, DHS, legislators, & other disability advocates to shape the development of the new waiver & voice concerns as they arise.



Self-Direction as a Way of Life



I choose the direction of my life, myself, or with the help of someone I trust!

Everyone deserves to live a life of value and meaning.

I am in the driver's seat of my life.

Self-Direction as a Way of Life

I am
Empowered

My Goals

My Hopes

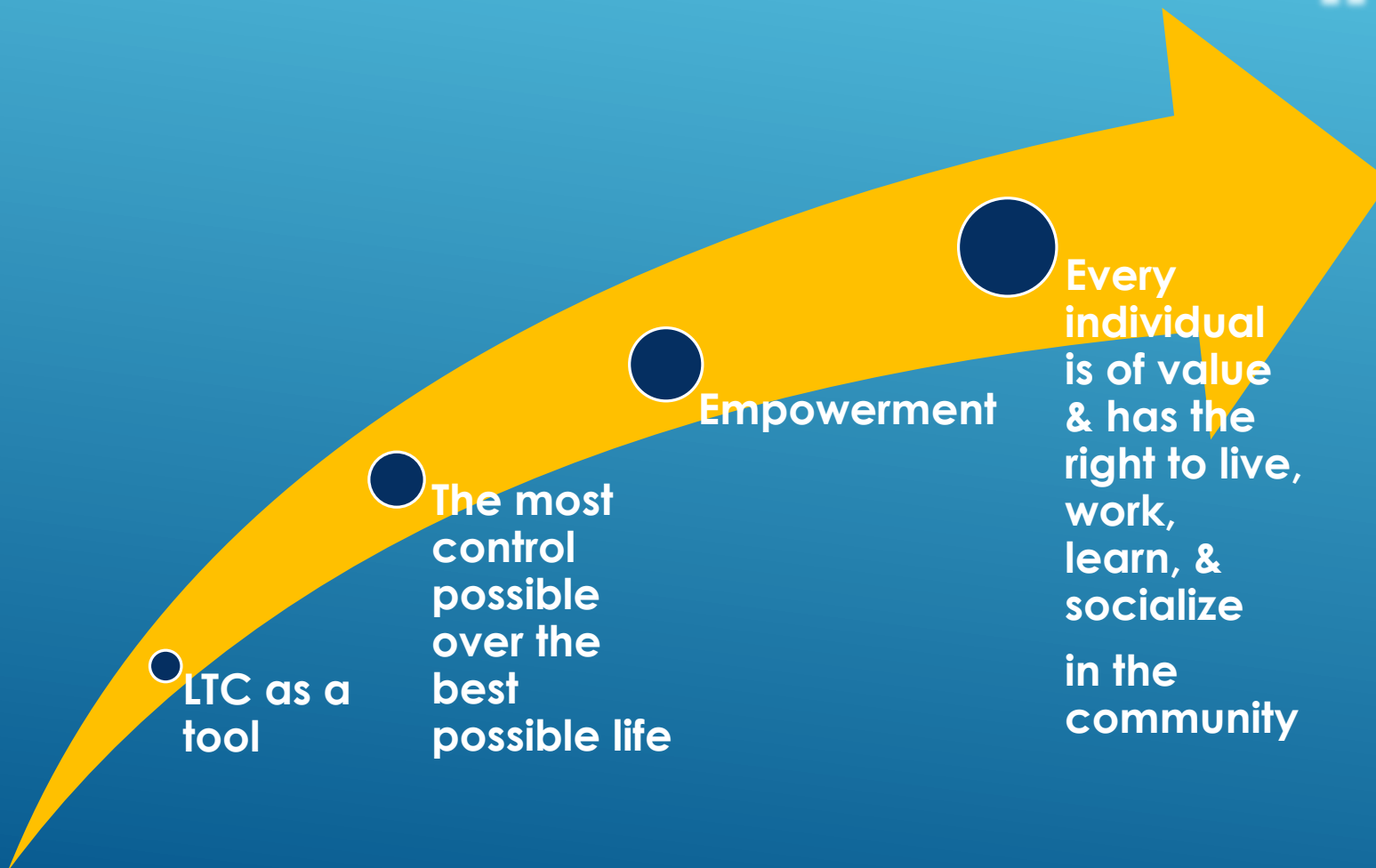
My Dreams

My Values



HOW DOES IT WORK?

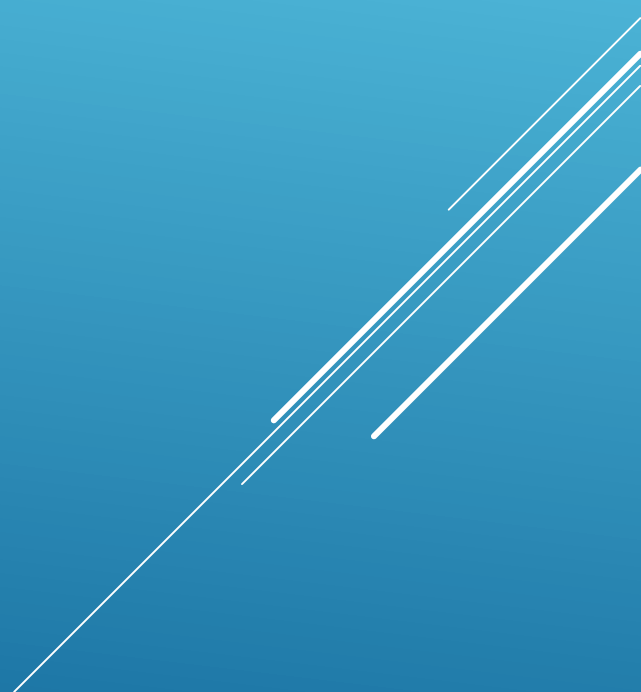
▶ Self-Direction as a Way of Life



“The Good Life”



SEEING POSSIBILITIES



What supports do I need...

To get ready
for my day

To access my
community,
my job, & my
appointments

To meet
my life
responsibilities

To be safe
and healthy

To do my job

SELF-DIRECTING YOUR LIFE TODAY

What are
my GOALS
for the
future?



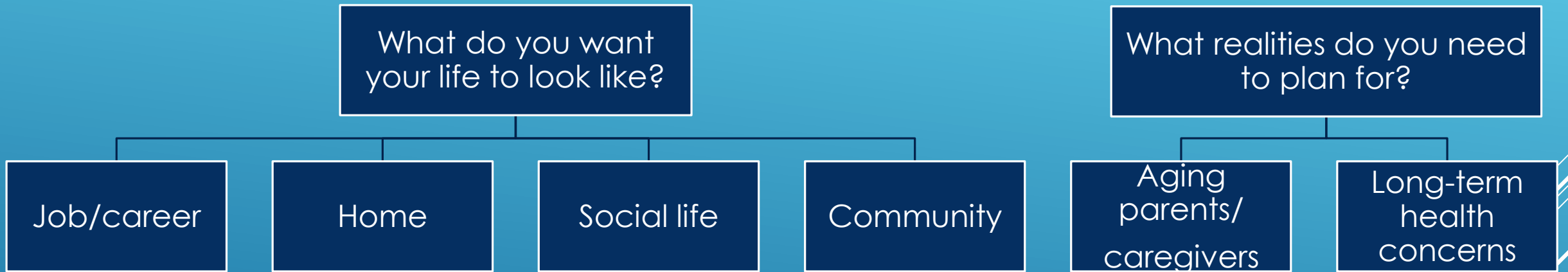
What is my
PLAN to
achieve
these goals?



SELF-DIRECTING YOUR FUTURE



GOALS



SELF-DIRECTING YOUR FUTURE



How do you get there?

PLAN

Create a Roadmap:

- Break your plan down into small pieces
- Set timeframes for achieving goals
- Find the resources to help you get there

Use a Person-centered planning process:

- PATH
- MAPS
- Personal Futures Planning

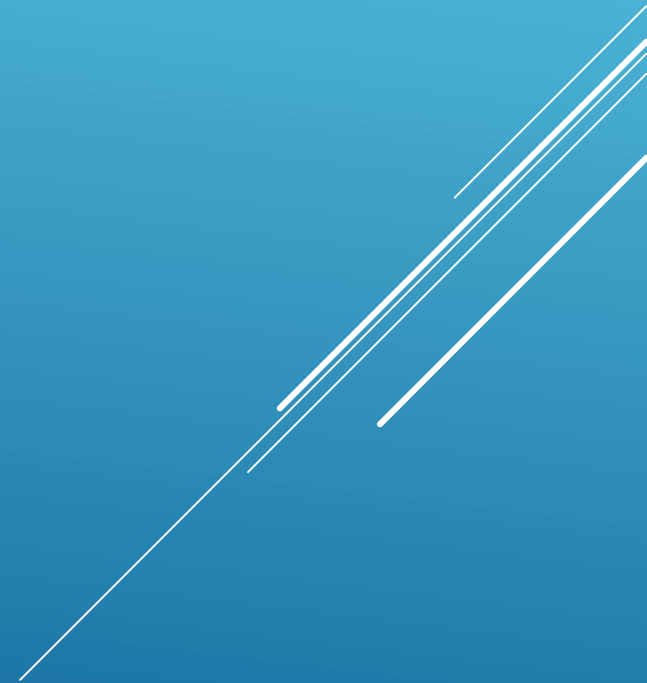
Build a Team:

- Circle
- Supported Decision-making Team
- Family-Governed Supports

SELF-DIRECTING YOUR FUTURE

The Purpose of a Plan

To provide a roadmap to help Kathryn achieve ALL of her community, employment and independent living goals. In addition, this plan establishes a roadmap to ensure that Kathryn can MAINTAIN her amazing life and self-directed supports infrastructure after the time her parents/primary caregivers can no longer participate.



Kathryn's Strategic 10 Year Plan

2015 Personal Care/Eating Healthy/Exercising

2016 Daily Planning/Social/Community/Dating

2017 Employment/Career

2018 Transportation

2019 Life Safety

2020 Homemaking

2021 Housing

2022 Benefits Eligibility Retention to Standby Guardian or Team

2023 Medical/Health Critical Decision Making to Standby Guardian or Team

2024 Financial Critical Decision Making to Standby Guardian or Team

Example: 2019 Life Safety

2015

- Uses social media safely
- Knows not to let strangers into her home when alone
- Learns to safely cross unmarked intersections and walk in parking lots

2016

- Demonstrates that she understands “circles of intimacy” (talk, trust and touch)
- Will understand “appropriate and inappropriate” relationships at work and within the community
- Will develop the confidence to trust her intuition if something/one feels unsafe
- Will be able to safely stay at home alone for one overnight

2017

- Knows what to do in the case of a fire, tornado warning or other emergency
- Know what to do and who to contact if something in her home is not working

2018

- Knows what to do in the case of an attempted robbery, assault or abduction
- Knows what to do if she spots someone on the sex offender list
- Knows how to stay safe on dates

2019

- Is able to SAFELY stay home alone for one week while parents are on vacation
- Will be ready to move out and live independently





CREATING THE GOOD LIFE
WHAT CAN WE DO RIGHT NOW?

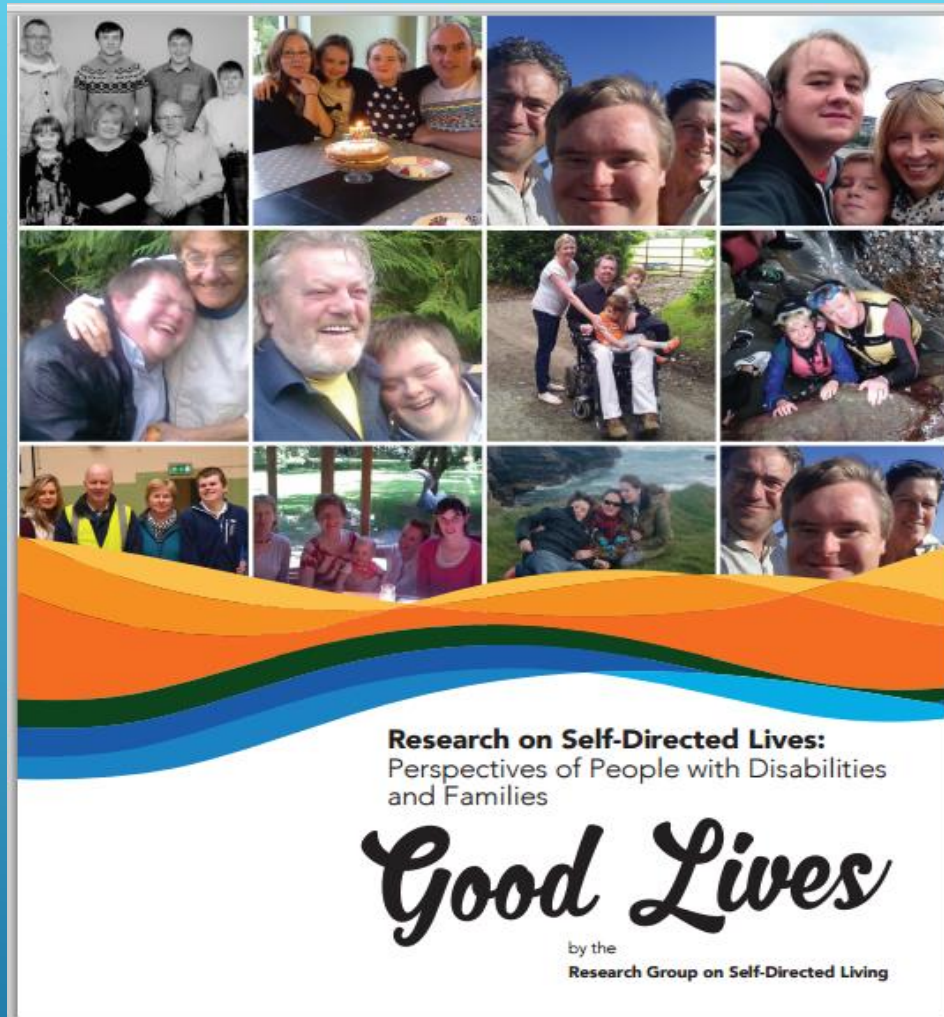


WHAT ARE YOUR DREAMS?

“Self-directed living is about stepping into your own power and setting the direction of your own lives by taking back some control and ownership.”

*– Rachel Cassen,
Member of Self-Directed Living Research Group*

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[HTTP://WWW.LEAPIRELAND.COM/](http://www.leapireland.com/)

1 . What we can do ourselves?

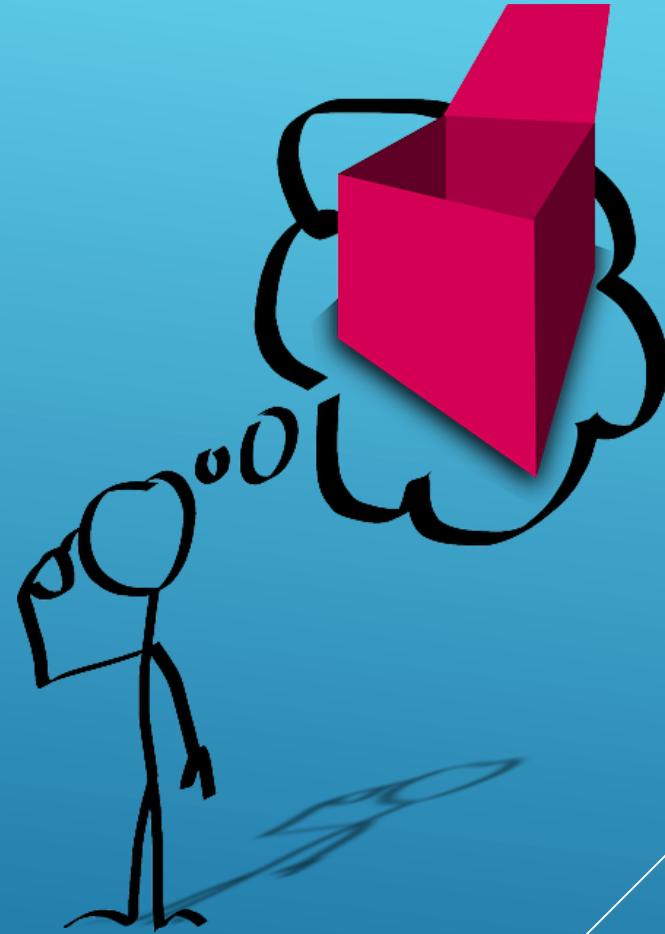
2 . What do we need support with?

3 . What can we create in partnership with others? .

Get Creative

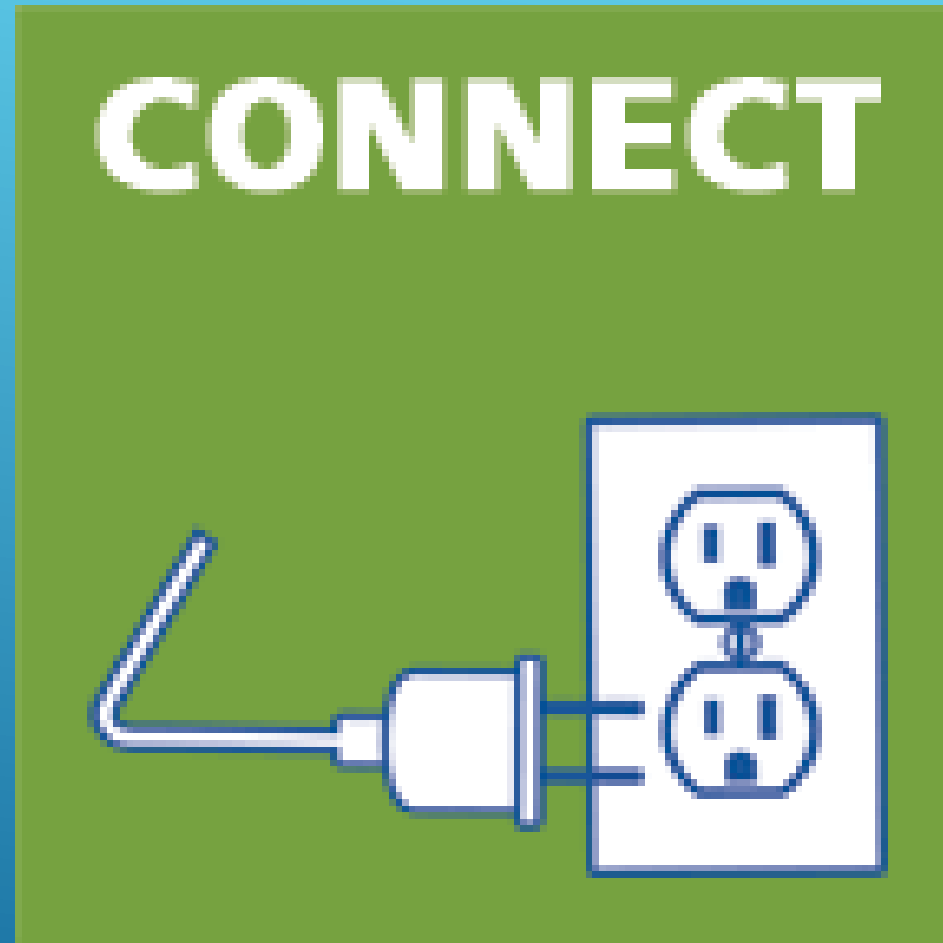
- ▶ Technology
- ▶ Low-tech
- ▶ Who is already in my life?
- ▶ Who can help?
- ▶ What is meaningful to me?

Think outside the box!



GET CONNECTED:

- ▶ Family groups
- ▶ Advocacy groups
- ▶ Social groups
- ▶ Online forums
- ▶ Facebook
- ▶ Twitter
- ▶ ??????????



Build Bridges

*“Be aware that relationships, friendships, lifestyle interests, work opportunities and living arrangements will not happen automatically . Begin to practice the ‘**art of asking**’ and of ‘**letting people in**’ to assist and guide you in supporting you and your family member.” -LEAP-Ireland*



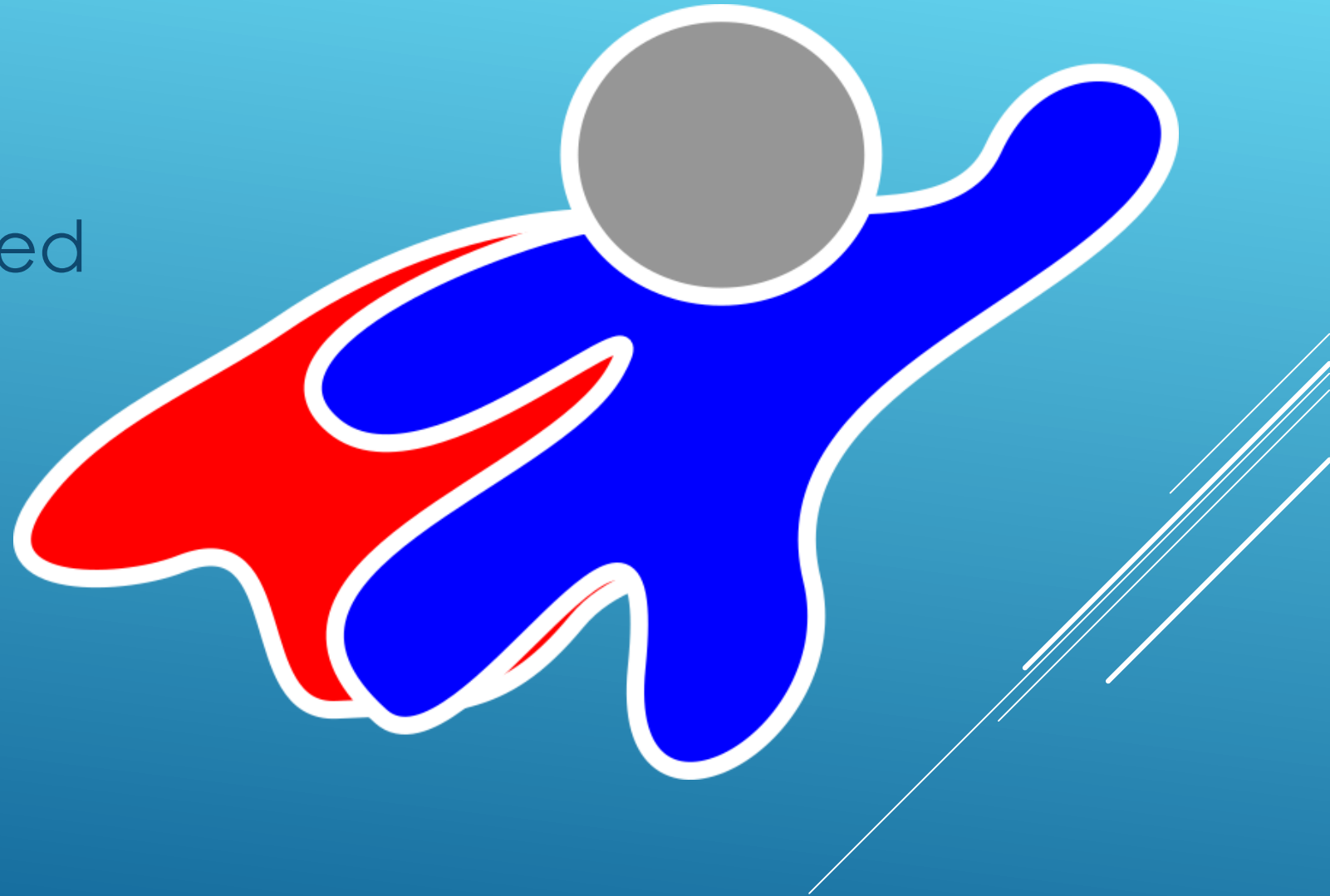
DEVELOP RELATIONSHIPS

- Family
- Friendships
- Workplace
- Volunteering
- Common Interests
- Social Groups
- Online Forums
- Facebook



EMBRACE YOUR VALUED ROLES

- ▶ Infinite possibilities
- ▶ What are your valued roles?



“In the end, self-direction isn't a program, it's a way of life!”

-Lynn Breedlove

“Planning for the future changes the present!”