You have **goals.**

You have

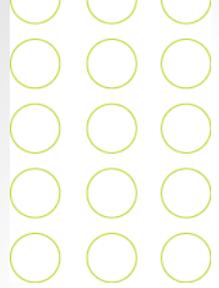dreams.

You have

ipmg

Charting a Course to a Good Life

Oct. 26, 2017

Heather Sorrells

IPMG Assistant Director of Case Management Operations

Acknowledgements

In preparation for this presentation, IPMG would like to thank and give credit to the following organizations. Due to their work in the area of Supporting Families Across a Lifespan, this slideshow has been developed. Reference and Resource information will be available at the end of this presentation. Thank you for your participation!
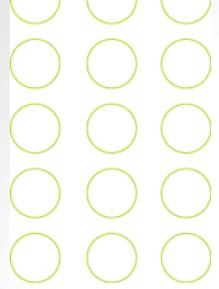
NASDDS

National Association of State Directors of Developmental Disabilities Services

AiD ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

HSRI

Human Services Research Institute

UMKC INSTITUTE FOR HUMAN DEVELOPMENT

A University Center for Excellence in Developmental Disabilities
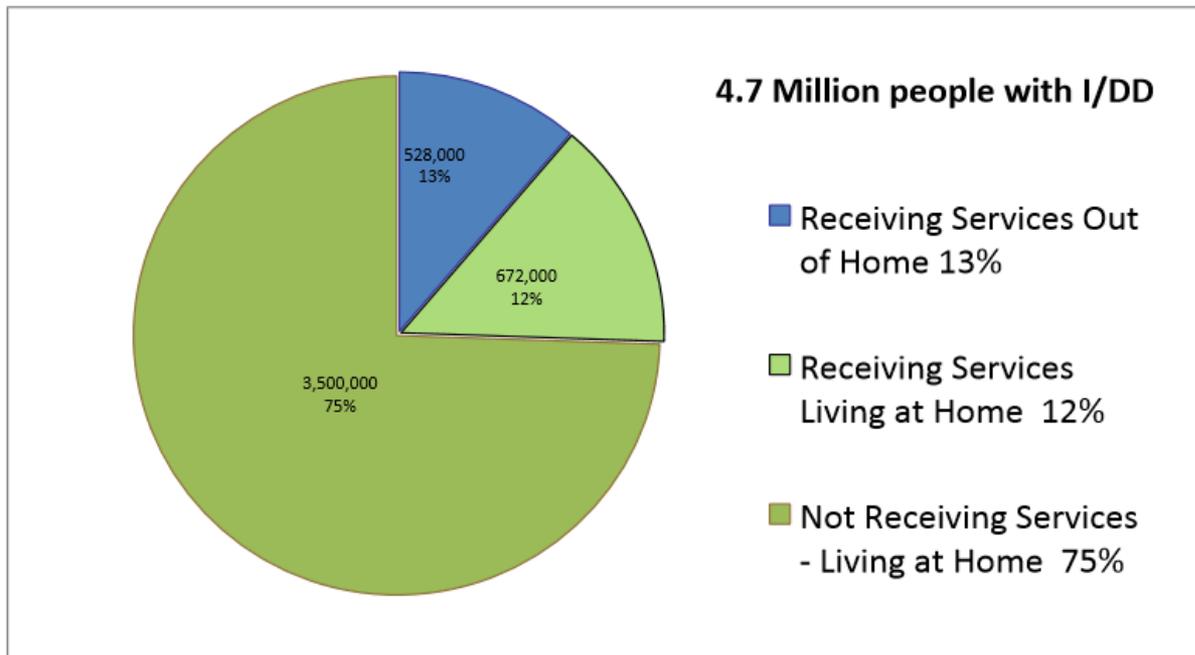
ipmg

Today's Agenda

o Current status and emerging national trends in supporting families and individuals with ID/DD

o Examine what it means to have a good life for individuals and families

o Strategies to assist case management professionals in implementing the LifeCourse Framework

ipmg

Importance of Family within the Context of Disability Services: Current Supports

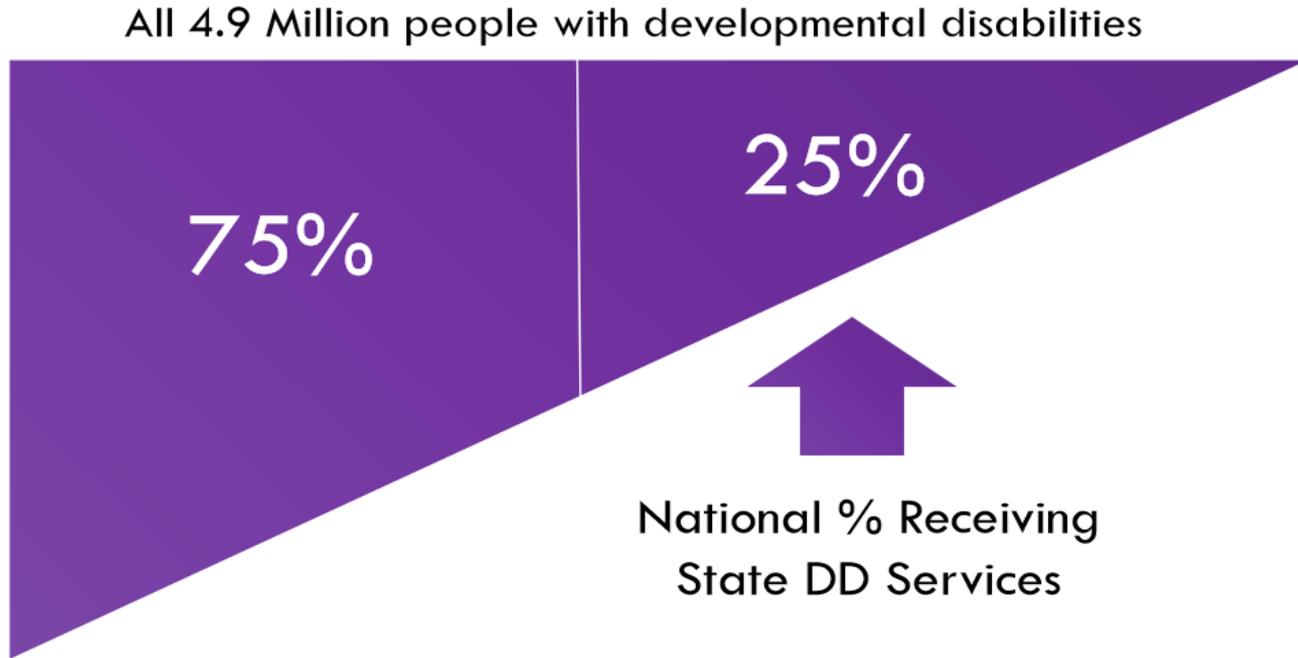*89% of People I/DD receiving services are Supported by Family*

4.7 Million people with I/DD

- 528,000
  13%

- 672,000
  12%

- 3,500,000
  75%

■ Receiving Services Out of Home 13%

□ Receiving Services Living at Home 12%

■ Not Receiving Services - Living at Home 75%

Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2000).

ipmg
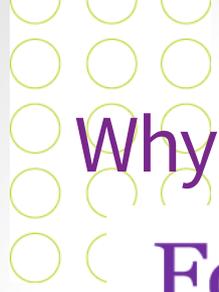
Why The Need For This National Discussion?

Focusing on ALL

All 4.9 Million people with developmental disabilities

75%

25%

↑

National % Receiving
State DD Services

Based on national definition of developmental disability with a prevalence rate of 1.49%
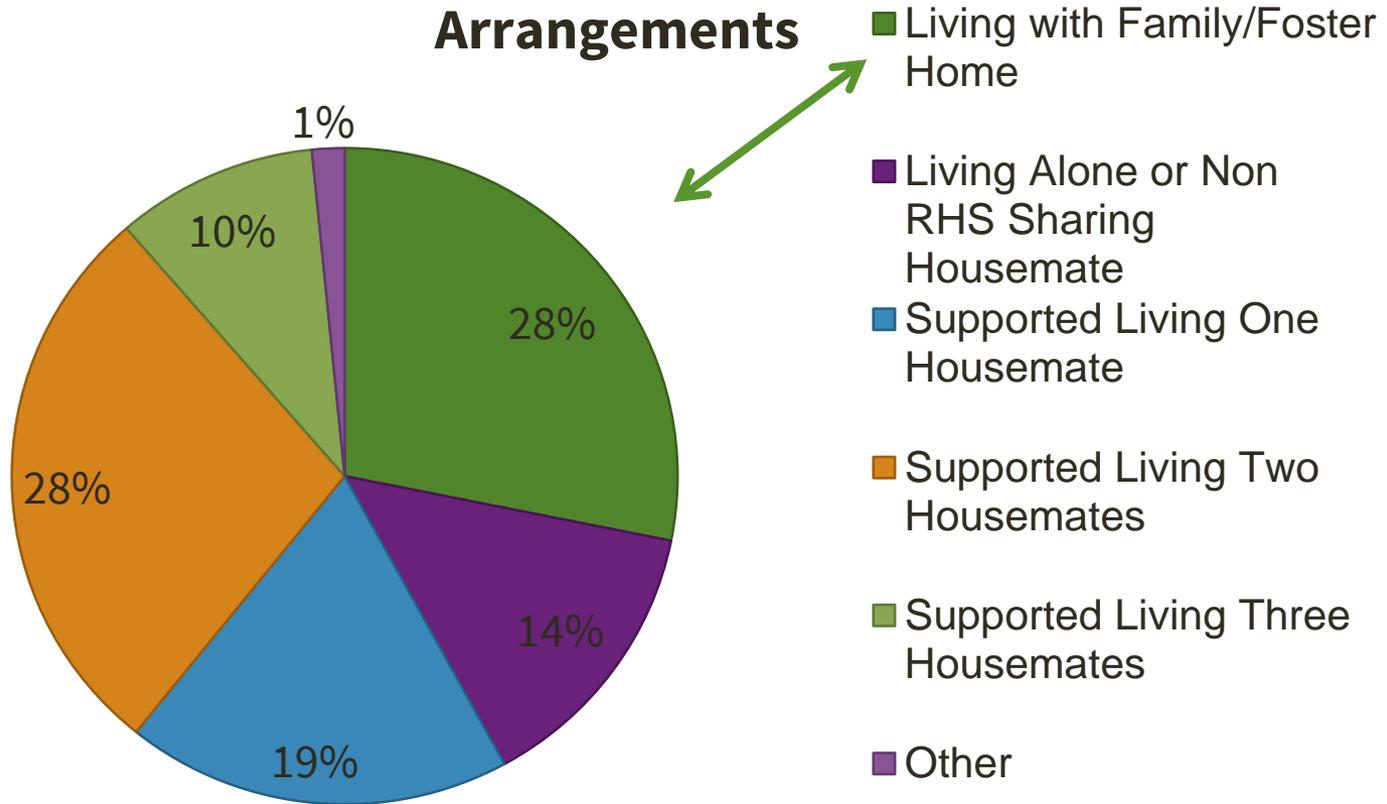
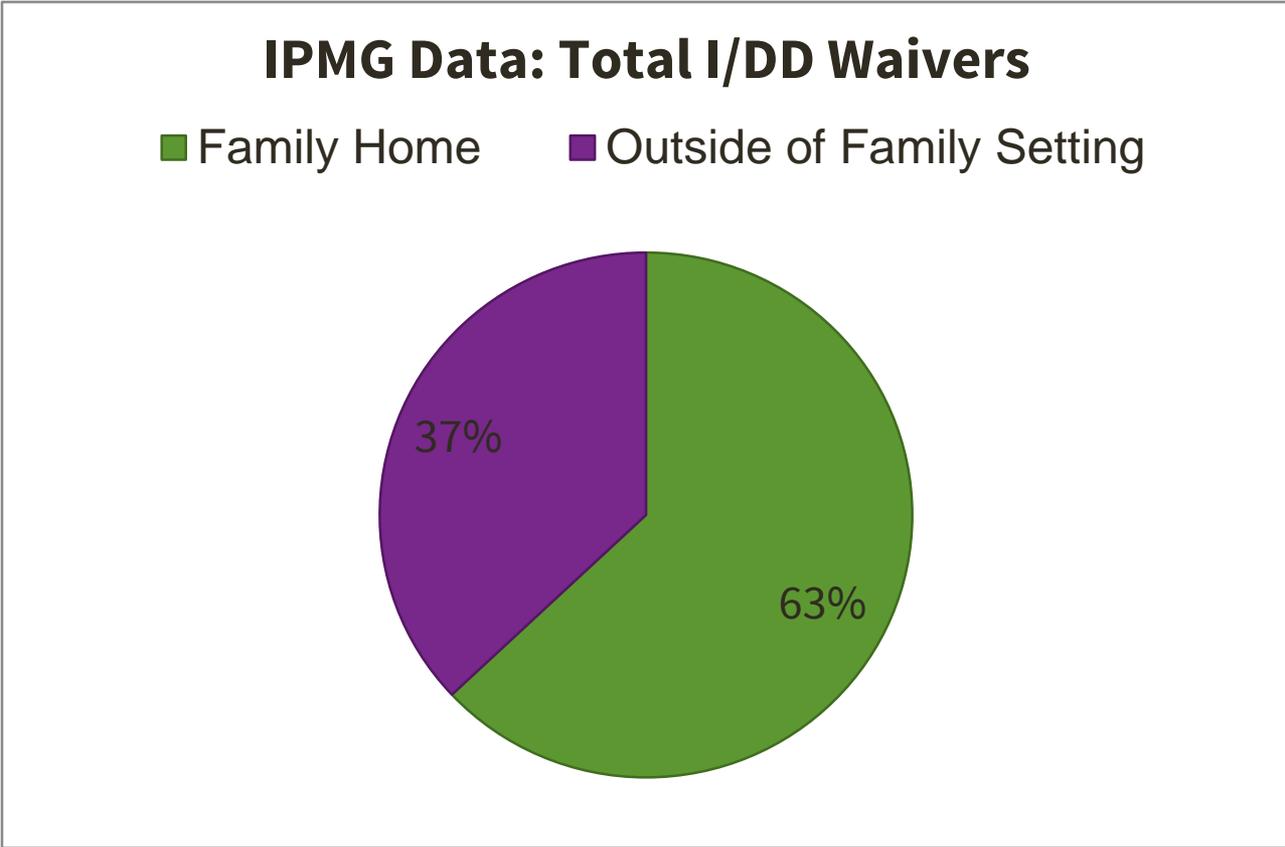Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities

ipmg

IPMG Trends: Family Setting - CIH


IPMG's Data: CIH Waiver by Living Arrangements

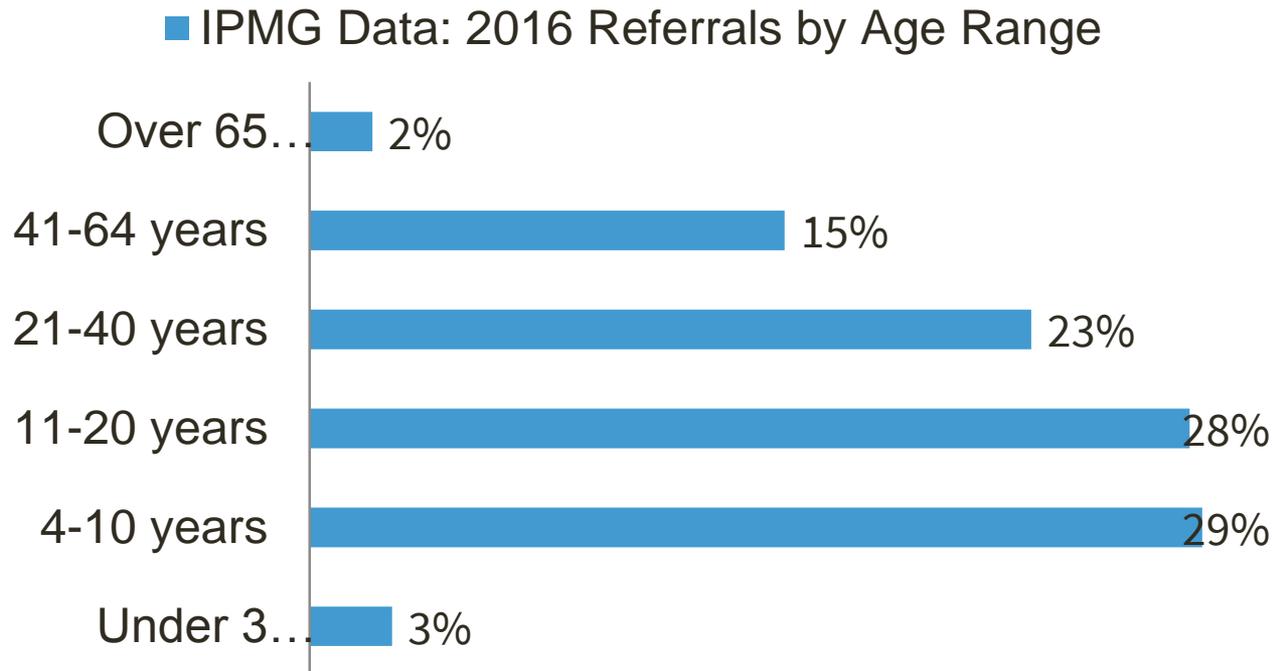- Living with Family/Foster Home
- Living Alone or Non RHS Sharing Housemate
- Supported Living One Housemate
- Supported Living Two Housemates
- Supported Living Three Housemates
- Other

Pie chart values: 28%, 14%, 19%, 28%, 10%, 1%

ipmg

IPMG Trends: Family Setting

IPMG Data: Total I/DD Waivers

- ■ Family Home
- ■ Outside of Family Setting

37%

63%

IPMG Trends: Age Range- All Waivers

IPMG Data: Individuals Served Age Ranges all Waivers

■ Individuals Served Age Ranges

Age Range	Percent
65 Over	5%
41-65 years	31%
21-40 years	45%
11-20 years	16%
0-10 years	3%
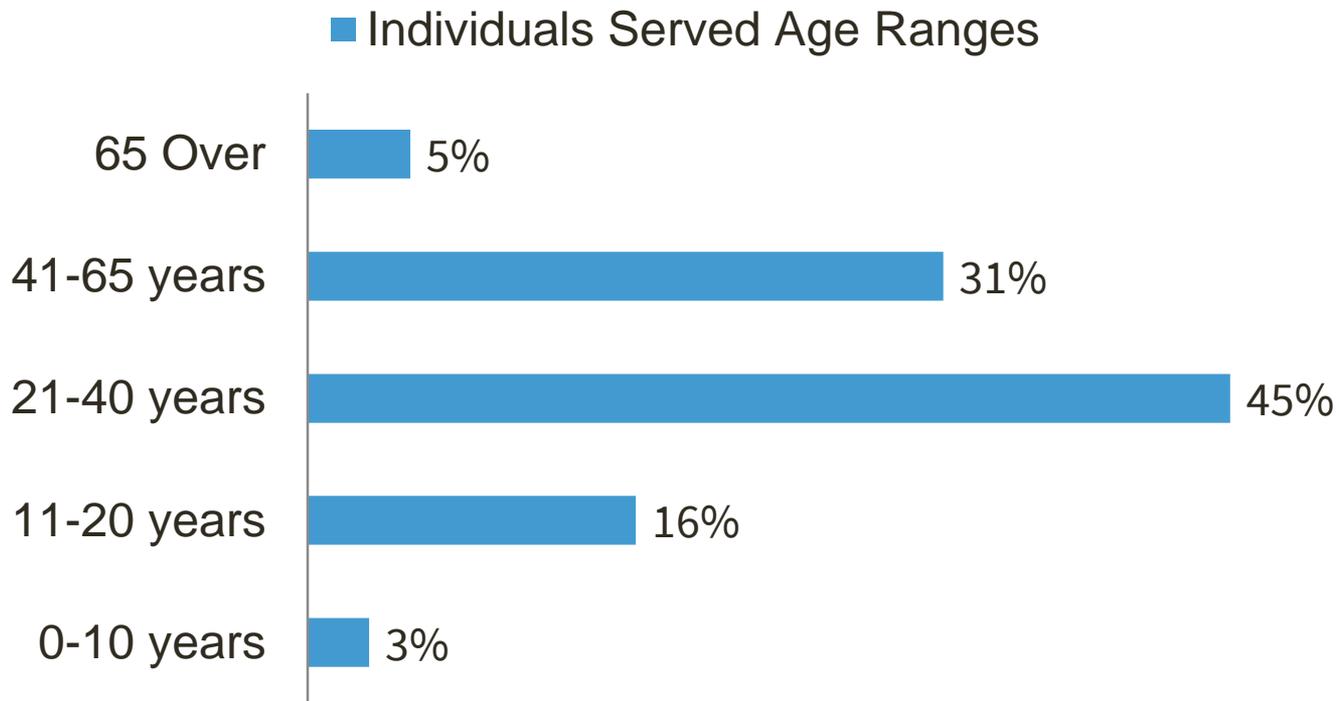
ipmg

IPMG Trends: Referrals 2016 by Age Range

IPMG Data: 2016 All Waivers Referrals by Age Range

■ IPMG Data: 2016 Referrals by Age Range

Age Range	Percentage
Over 65…	2%
41-64 years	15%
21-40 years	23%
11-20 years	28%
4-10 years	29%
Under 3…	3%

ipmg

The CORE of a Good Life: Guided Conversations with Parents on Raising Young Children with Disabilities

"When we talked with parents and providers, they said that many of their conversations focused on finding professional services and resources. They were seeking therapies and interventions to fix the problems their children faced. Both parents and providers spoke of the pressure, stress and frustration this created."
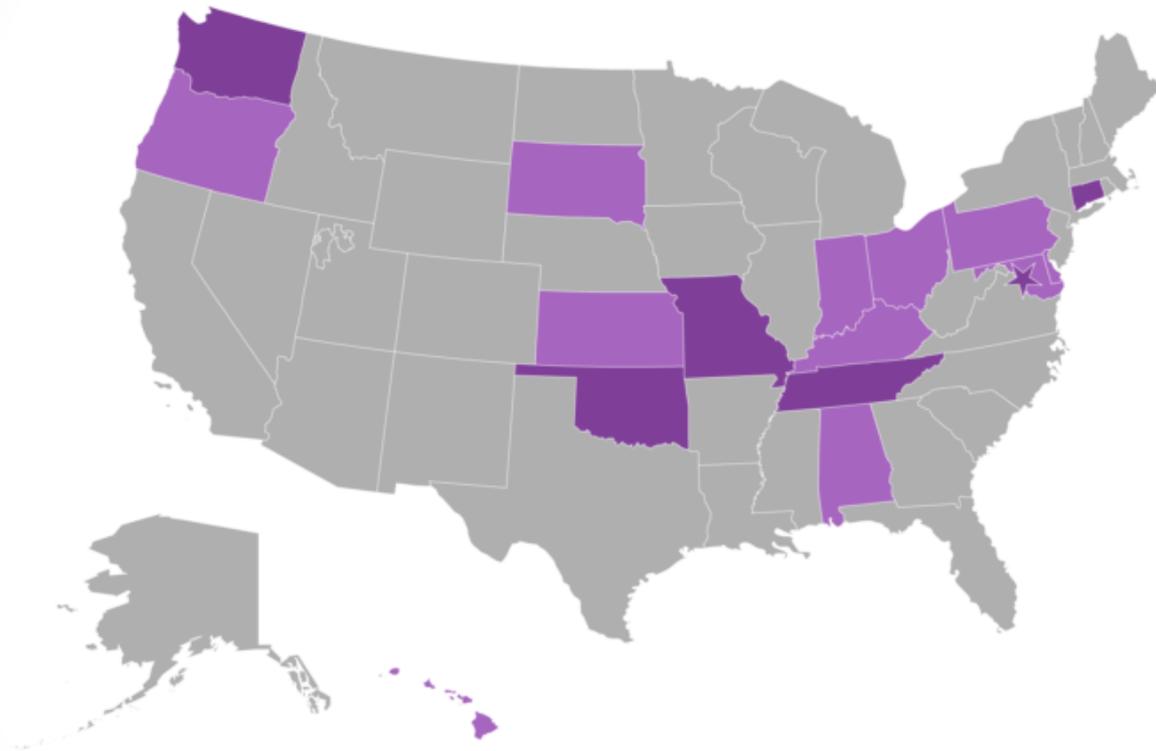
WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities

Molly Murphy, Ph.D.& Mark Sweet, Ph.D.

Strategies for Supporting Families

Supporting families requires a comprehensive and coordinated infrastructure that includes the following strategies:

- o Education and training

- o Connections to other

- o Collaborative

- o Navigating and accessing services and supports

8/31/2017

From the National Agenda on Supports to Families, 2011

ipmg

1
1

The Supporting Families Project

The *Supporting Families* project is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012.
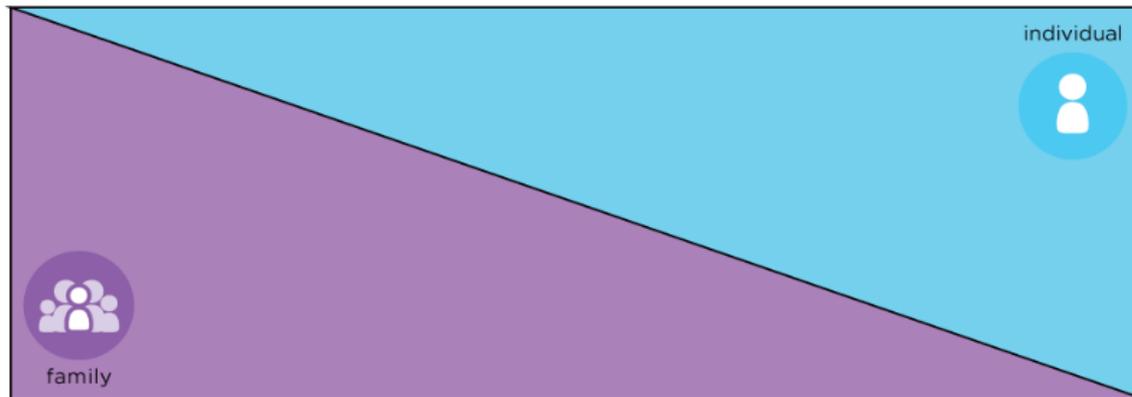
ipmg
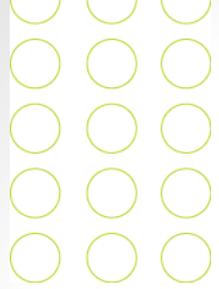
Core Belief

All people have the right to live, love, work, play and pursue their life aspirations in their community.

8/31/2017

# Recognition of Individual and Family Cycles

Individual Life Cycle

Family Life Cycle

Thinking Across All Life Domains

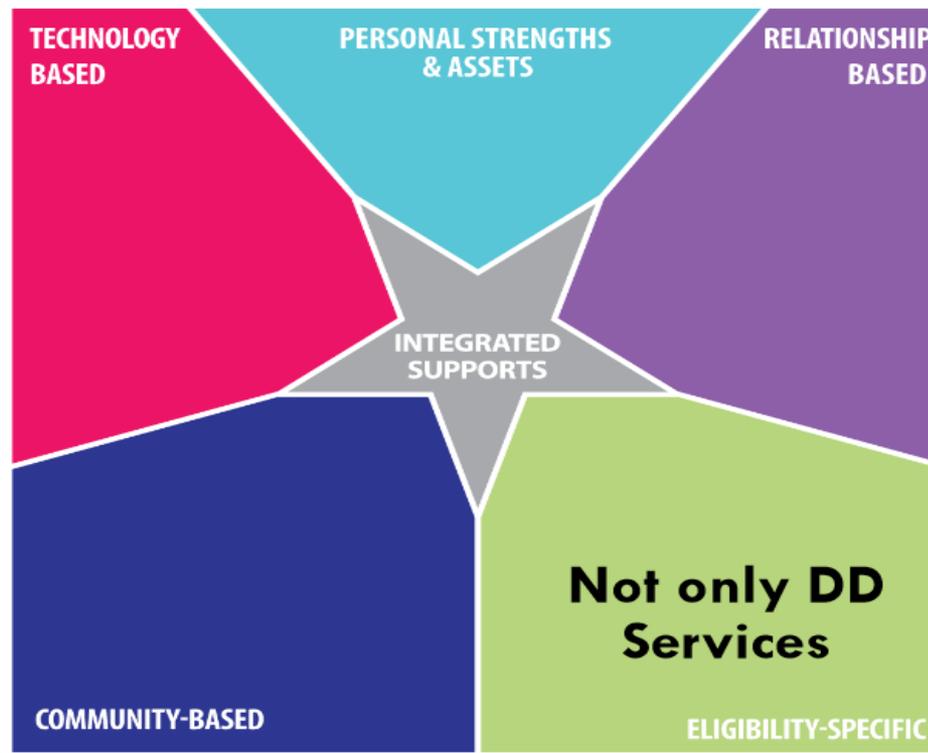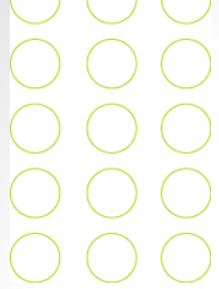|			
Daily Life & Employment	What a person does as part of everyday life – school, employment, volunteering, routines, life skills	**Healthy Living**	Managing and accessing health care & staying well – medical, mental health, behavioral health, developmental, wellness & nutrition
Community Living	Where and how someone lives – housing and living options, community access, transportation, home adaptations & modifications	**Safety & Security**	Staying safe and secure – emergencies, well-being, guardianship options and alternatives, legal rights and issues
Social & Spirituality	Building friendships and relationships, leisure activities, personal networks, faith community	**Citizenship & Advocacy**	Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived

ipmg
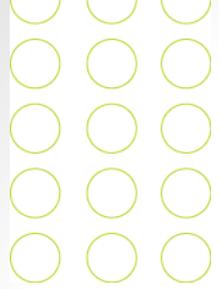
THREE BUCKETS

Three Types of Supports

Discovery & Navigation

Connecting & Networking

Goods & Services

8/31/2017

ipmg
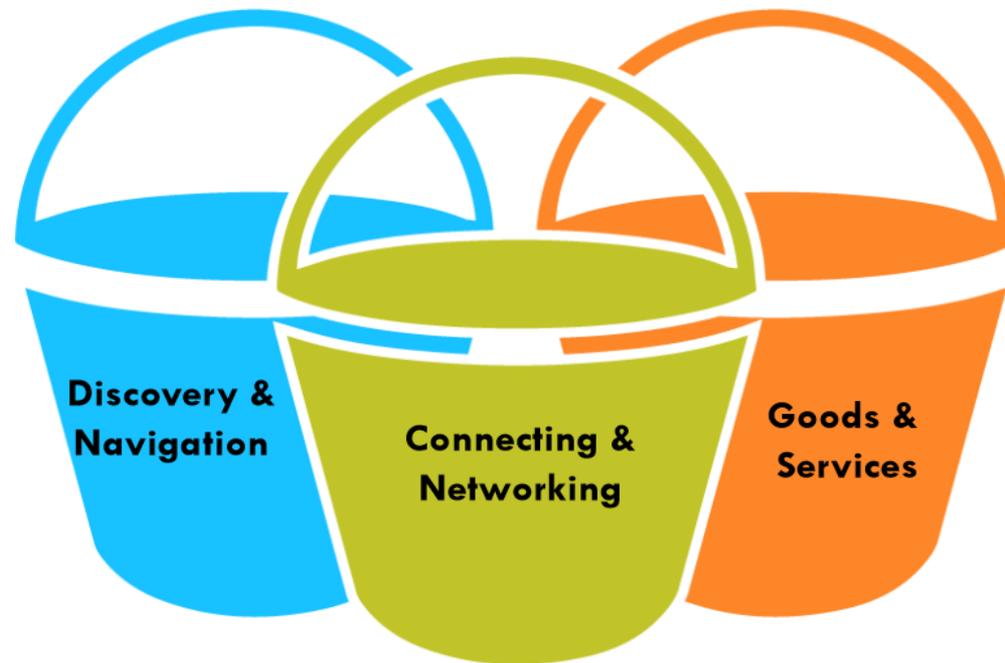
Identifying Integrated Strategies for Delivery Supports

Lifespan Supports

o Different supports are needed across each life stage

o Each period of life comes with it's own rewards and challenges
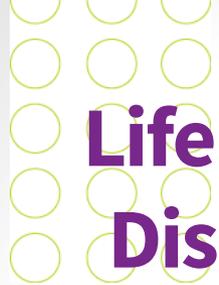
o Link to more than just paid services

Starting a New Family Journey
Infancy 0-3

➢ Education

➢ Advocacy

➢ Networking

➢ Developing Vision

STARTING A NEW FAMILY JOURNEY

Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities

ipmg

Life Domain Discussion

Community Living :

➢ Housing and Living Options

➢ Community Access

➢ Home Adaptations and Modifications

➢ Transportation

What does the individual want and need now?
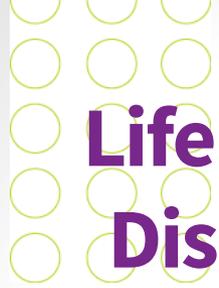
What is the Vision for the future?

ipmg

Early Childhood
Ages 4-6

➢ Training and information to become an empowered advocate

➢ Access to integrated inclusive experiences

➢ Early education services and supports

EARLY CHILDHOOD

Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities
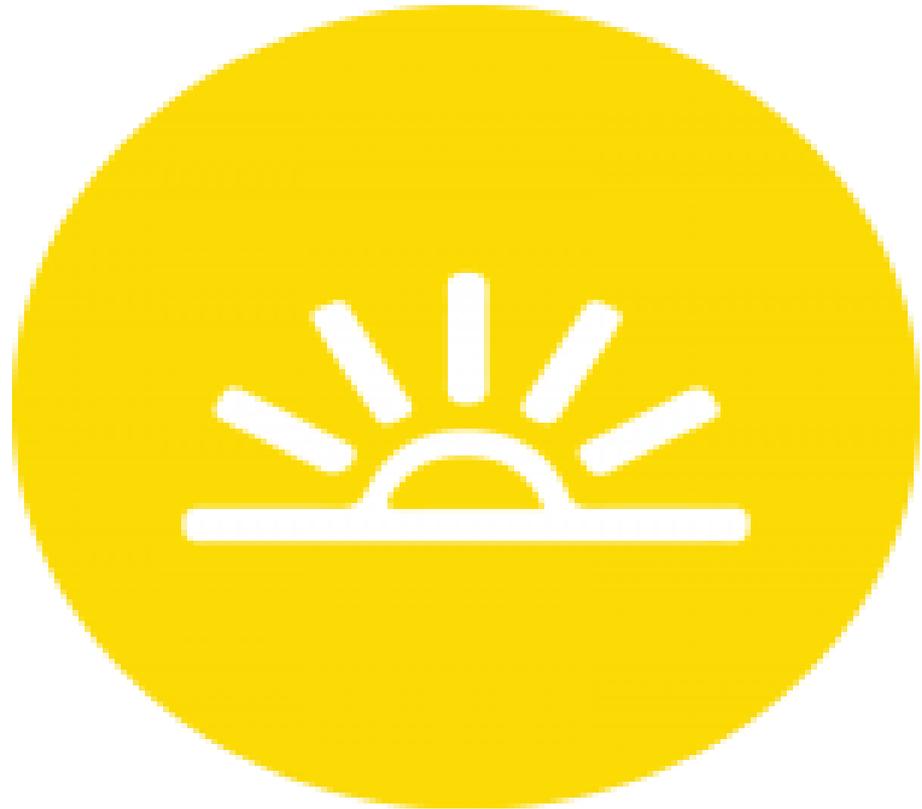
ipmg

Life Domain Discussion

Daily Life & Employment :

- ➤ What someone does everyday
- ➤ School, Job, Volunteer
- ➤ Life Skills
- ➤ Routines
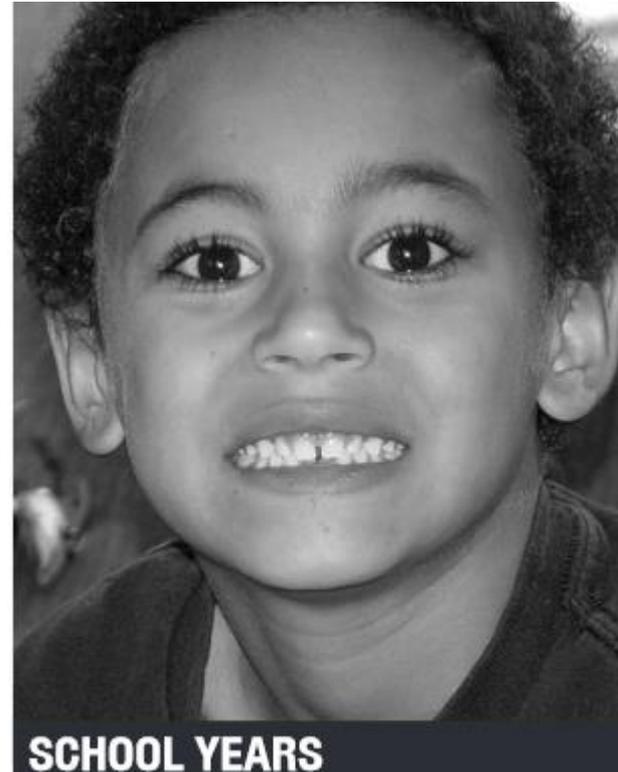
What does the individual want and need now?

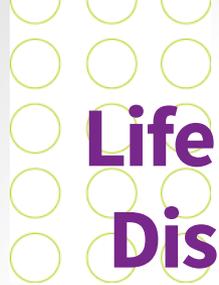**What is the Vision for the future?**

ipmg

School Years
(Elementary and Middle)
Ages 6-13

➢ Advocacy and training in best practices (inclusion, self-determination, future planning etc.)

➢ Community contacts inside and outside of the disability world

➢ Increased relationships and networks that provide natural supports

SCHOOL YEARS

Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities

ipmg

Life Domain Discussion

Social & Spirituality :

➢ Building Friendships and Relationships

➢ Leisure Activities

➢ Personal Network

➢ Faith Community

What does the individual want and need now?
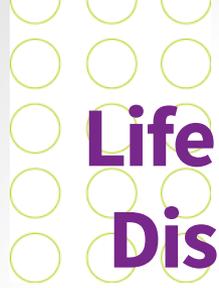
What is the Vision for the future?

ipmg

Transition To Adulthood (High School Transition) Ages 14-21

➢ Plan for life after school

➢ Decision-Making Skills

➢ Increased independent living

.

TRANSITION TO ADULTHOOD

Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities

ipmg

Life Domain Discussion

Safety & Security :

➤ Emergencies

➤ Well-being

➤ Legal Rights

What does the individual want and need now?

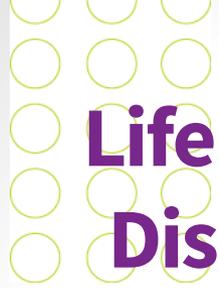**What is the Vision for the future?**

ipmg

Adult Life
Ages 22- 62

"The adult family member moves toward a self-determined life on his or her own, that includes beginning to search for work, find a place to call home, choose friends, including sexual partners, and maybe decide to start his or her own family."

ADULT LIFE

Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities

ipmg

Life Domain Discussion

Citizenship & Advocacy :

➢ Building Valued Roles

➢ Choice Making

➢ Goal Setting

➢ Driving One's own life

What does the individual want and need now?
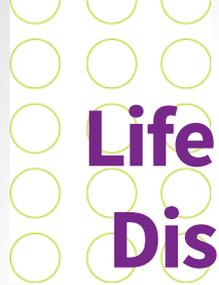
What is the Vision for the future?

![ipmg logo]

Golden Years (Retirement) Ages 62 and Older

Was sufficient planning done in the past?

GOLDEN YEARS

Building A National Agenda For Supporting Families With A Member With Intellectual And Developmental Disabilities

ipmg

Life Domain Discussion

Health Living :

➢ Accessing and Managing Healthcare

➢ Staying well

What does the individual want and need now?

What is the Vision for the future?

ipmg

Supporting Families Strategies

Supporting families requires a comprehensive and coordinated infrastructure that includes the following strategies:

- o Funding for goods and services specific to the support and/or caregiving role for the person with I/DD across the lifespan (e. g., respite, home modifications, cash assistance, assistive technology)
- o Plan for crisis prevention/intervention for families and other caregivers
- o Training to enhance the family's ability to advocate for services and policies
- o System for accountability and quality assurance through data collection, evaluation and feedback loop components

From the National Agenda on Supports to Families, 2011

ipmg