2023 Supporting Families Survey Results

Support Families Throughout the Lifespan Quality Management Plan

Office of Developmental Programs

The Office of Developmental Programs (ODP), has a Supporting Families Statewide Leadership Team with members from ODP, the PA Developmental Disabilities Council (PADDC), the PA Family Network, Self Advocates Power Network For All (SAPNA), and Early Intervention Technical Assistance (EITA). With ODP and the PADDC partnering as the lead, this team guides the activities of PA's Community of Practice (CoP) for Supporting Families, which is part of the National CoP for Supporting Families.

Why did we conduct this survey?

In 2019, we decided that we would like to have a quality management plan. The purpose of a quality management plan is to try to make something better by really focusing on improving the quality of something.

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Wingspread Report, 2012

"Supporting families means that **resources flow to those who need** them the most, **when they need them** the most, **with an array of desirable options** for support." Preface, page 3

ISAC Recommendation 4: Support Families throughout the Lifespan

"**Families need information, resources, and training**. They need connections with other families and support services. Listening to people with disabilities and their families is key to providing supports that help them achieve an everyday life."

3/7/2024

3

Using what we have learned by being part of the National CoP for Supporting Families as well as from ODP's Everyday Lives vision and values, we focused on what it means to support families. The Wingspread Report from 2012 defines what supporting families means. And ODP's ISAC (Information Sharing Advisory Committee) Recommendation 4 gives us more advice.

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Goal: **Families are supported**

Outcome: Families and individuals receive information and support when and how they need it.

Target Objective: Increase % of family members who report SCs help them get the support they need when and how they need it by 5% to 75% by June 30, 2023.

We used that information to set a goal, desired outcome, and target objective for our quality management plan. Our goal is that families are supported.

Question: What does goal mean?
Answer: The goal is what we want.

Question: Who do we mean when we say families?
Answer: Families include any members of the family as defined by the person. Families include the person with an intellectual developmental disability and/or Autism (IDD/A). We will use the word "individual" to refer to the person with IDD/A.

Question: What does outcome mean?
Answer: The outcome is how we define what the goal means a little more specifically.

Question: Why is the outcome that families and individuals receive information and support when and how they need it?
Answer: We used the definition from the Wingspread Report and ISAC Recommendation 4 to explain how we can learn if families are supported.

Question: What do we mean by support?

Answer: Support means any goods and or services (paid or unpaid) for the person and their family across life domains (all parts of their lives) and the lifespan (their   whole life, whatever age they are).

Question: What is the target objective?
Answer: The target objective tells how we can tell if the outcome is being reached. Our target objective shows that we hope that the percentage will get higher from   the first time that we did the survey in 2021.

Question: Why did we use the supports coordinator (SC) in our target objective?
Answer: The SC is the person in the ODP service system who has the job to locate, coordinator, and monitor needed services and supports. That means that the SC is   helping people have the information and support that they need.
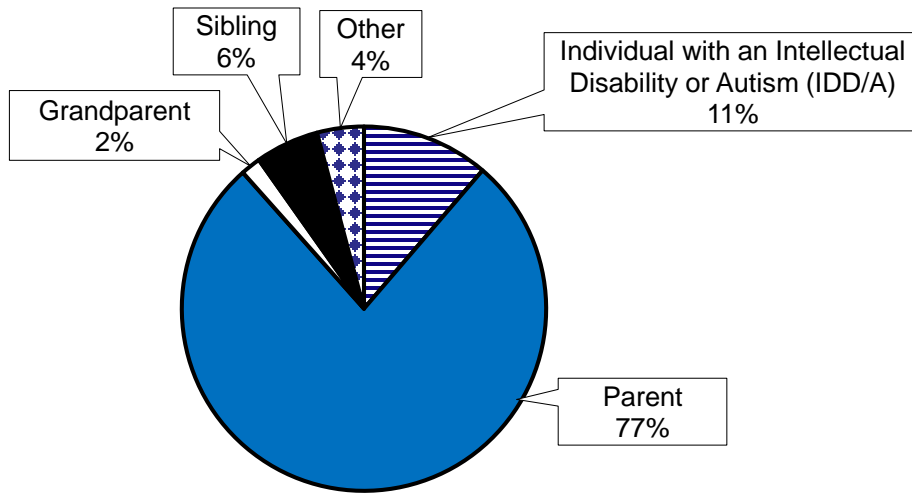
We decided that we needed a survey to see how families are supported.

Who took the survey?

When we talk about families, we mean the whole family as defined by the person.

The first survey that we did in 2021 did not include individuals. That's because it was hard to make the survey for the whole family. We thought that we would conduct a second survey that year for individuals, but we learned that making the survey and reviewing all of the results takes a lot of time. This time, we decided that the 2023 survey had to be created so that any family member could take it.

Who took the Survey? Relationships

Sibling 6%
Other 4%
Grandparent 2%
Individual with an Intellectual Disability or Autism (IDD/A) 11%
Parent 77%

Who took the Survey in 2023? 337 individuals and family members

These are the results:

Response	Percent	Number of responses
I have a Supports Coordinator	11.28%	38
I am the parent of a person who has a Supports Coordinator	77.15%	260
I am the grandparent of a person who has a Supports Coordinator	1.78%	6
I am the sibling of a person who has a Supports Coordinator	5.64%	19
I have a different relationship with a person who has a Supports Coordinator	4.15%	14
Total	100.00%	337

Race
- 87% White

Ethnicity
- 84% Not Hispanic or Latino

Language at spoken at home
- 94% English

We asked several questions to learn more about the person taking the survey and the individual. The questions are to help us understand if we are hearing from diverse populations, or specific populations. It helps us to understand the results.

What is your ethnicity?

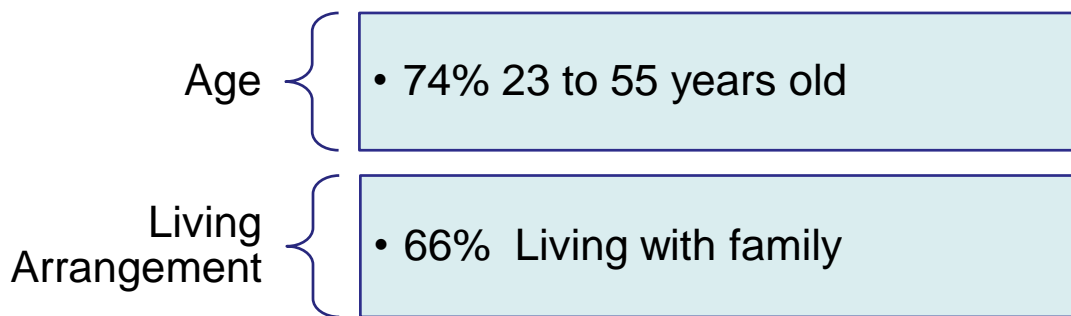| Answer	Percent(%)	Count(N)
Hispanic or Latino	2.64%	9
Not Hispanic or Latino	83.87%	286
I prefer not to answer	13.49%	46
Total	100.00%	341

What is your race? Note: Mark one or more races to indicate what you consider your race to be.

Answer	Percent(%)	Count(N)
American Indian or Alaska Native	0.59%	2
Asian	1.17%	4
Black or African American	2.35%	8
Native Hawaiian or Other Pacific Islander	0.00%	0
White	87.10%	297
I prefer not to answer	8.21%	28

9

Other - I self-identify as:	0.59%	2
Total	100.00%	341

Do you use a language other than English at home?

Answer	Percent(%)	Count(N)
Yes	5.87%	20
No	94.13%	321
Total	100.00%	341

Age { • 74% 23 to 55 years old

Living Arrangement { • 66% Living with family

How old is the person who has a Supports Coordinator?

Answer	Percent(%)	Count(N)
Under 3 years old	0.33%	1
3 to 5 years old	0.00%	0
5 to 14 years old	4.35%	13
15 to 22 years old	16.05%	48
23 to 55 years old	73.91%	221
56 years old or older	5.35%	16
Total	100.00%	299

Where does the person who has a Supports Coordinator live? Note: If you choose "somewhere else," you will be prompted to enter that place in a text box that will appear.

| Answer	Percent(%)	Count(N)
In own home/apartment	17.01%	58
A home/apartment shared with other people (not family like roommates)	1.76%	6
A home/apartment shared with family members	65.98%	225
In a LifeSharing home	2.05%	7

In a home where a provider supports 4 or less people	11.14%	38
In a home where a provider supports 5 to 15 people	0.59%	2
In a center where a provider supports 16 or more people (private ICF)	0.00%	0
In a State-operated Center (Ebensburg or Selinsgrove)	0.00%	0
In a Personal Care Home	0.59%	2
In a Nursing Home	0.00%	0
Somewhere else	0.88%	3
Total	100.00%	341

What are the results and data from the survey?

Now that we know more about the people who took the survey, lets look at what they had to say.
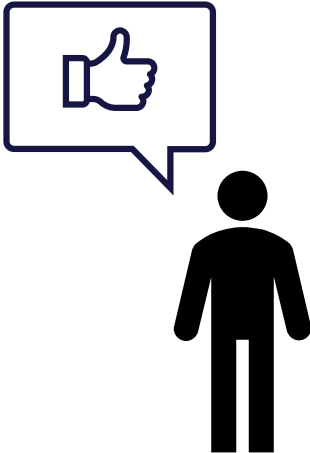
We asked the same main question in the 2023 survey that we asked in the 2021 survey. That is so that we can have a direct comparison.

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Does your Supports Coordinator get you the information and support you need when and how you need it?

	Yes	Sometimes	No
2021	70%	24%	6%
2023	68%	24%	8%

□ 2021 ■ 2023
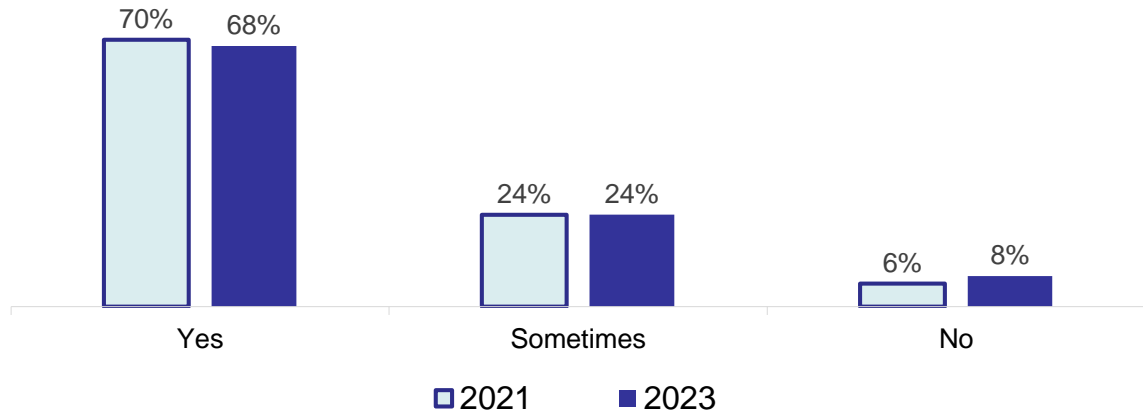
3/7/2024   13

While we hoped to see the % increase to 75%, the results are very similar, and instead went down a little bit. During the two years between the surveys, we know that a lot happened to influence satisfaction with support received by the SC. The pandemic continued to have effects on families needs, SC staffing, and so much more.
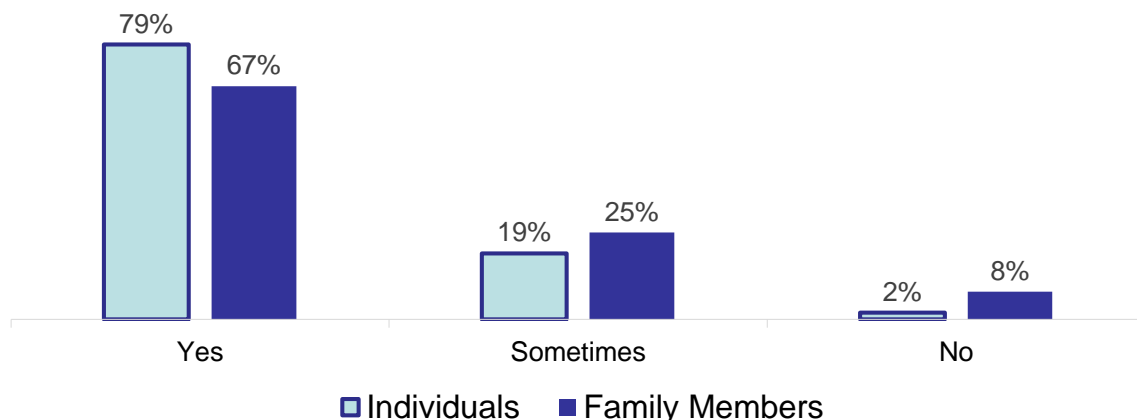
2021 Baseline Survey Responses

70%   Yes

6%   No

24%   Sometimes

2023 Survey Responses

68%   Yes
8%   No
24%   Sometimes

13

Does your Supports Coordinator get you the information and support you need when and how you need it?

	Yes	Sometimes	No
Individuals	79%	19%	2%
Family Members	67%	25%	8%

□ Individuals ■ Family Members

Because we were able to include individuals in this survey, we wanted to know the baseline results from their perspective. We also wanted to know if the individuals' responses were very different from the family members' responses. While this is helpful to look at and discuss, we really want to focus on the whole family, so the combined responses are still important.

Here is how individuals and family members responded:

Individuals
Yes   79%
Sometimes   19%
No   2%

Families
Yes   67%
Sometimes   25%
No   8%

More about *What*, *When*, and *How*?

When we reviewed the results from the first survey in 2021, we learned a lot about how to ask better and different questions.

So, in the 2023 Survey, we wanted to learn more about whether people have *information* and *support, when* they need it and *how* they need it. So we asked a few more questions.

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Always got me **what** I needed.

68% Agree or Strongly Agree

3/7/2024

17

We decided to ask about the last 6 months because we wanted to know about families' current experiences. We first asked if they had contact with their SC during the prior 6 months. We learned that most who had contact with their SC in the last 6 months either agreed or strongly agreed that the SC always got them what they needed.

Because this was the first time to include individuals, we checked their ratings (67%) compared with family members (68%) and found no real difference.

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Got me what I needed **when** I needed it.

67% Agree or Strongly Agree

3/7/2024

19

Most who had contact with their SC in the last 6 months also either agreed or strongly agreed that the SC always got them what they needed.

Because this was the first time to include individuals, we checked their ratings (67%) compared with family members (67%). They were exactly the same.

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Is that **how** you wanted to get what you needed? *(after being asked how they received it)*

98% Yes

3/7/2024

21

To learn about whether people got what they needed HOW they needed it, we focused on how information was provided. So, we asked how SCs shared information and then asked if that was how they wanted to receive the information. People are satisfied with how they receive information.

Totals

Yes	229 (98%)
No	4

How did people receive the information?

Email	153
Phone call	172
Text	60
In a meeting	144
Remote monitoring	19
A different way	27

I did not need anything — 5%
Something else — 7%
Coming up with ideas — 15%
Technology — 4%
Connections — 7%
Paid Services — 18%
Community resources — 18%
Information — 25%
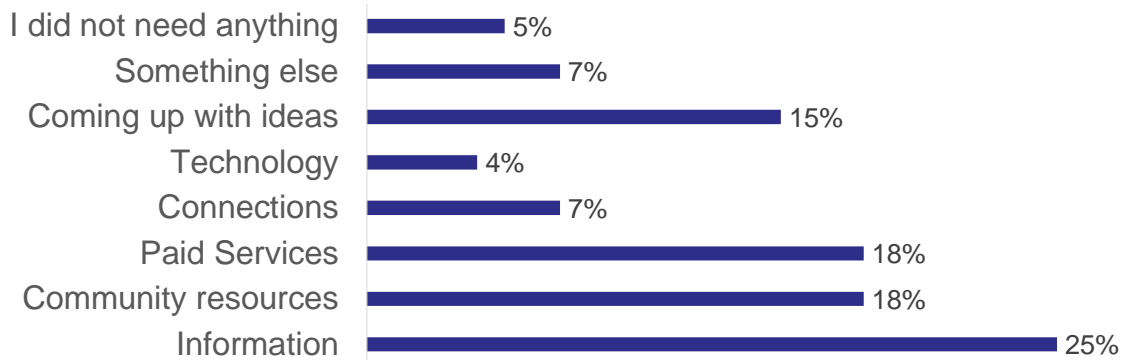
3/7/2024   22

To learn what types of information and support families needed, we gave them a list of things and then asked them to pick as many as were true for them. Information was the top thing that families needed. The next highest things that families needed their SC to help them with were to access paid services and community resources. Both are important!

We used the LifeCourse principle about integrated supports to create the list in this survey.

Integrated Services and Supports Across the LifeCourse Integrated Supports Star – LifeCourse Nexus (lifecoursetools.com)
Individuals and families access an array of integrated supports to achieve their envisioned good life. These include those that are publicly or privately funded and based upon eligibility; community supports that are available to anyone; relationship-based supports; technology; and the personal strengths and assets of the individual and their family.

Community Resources – A New Tool in PA

[PA Navigate by findhelp - Search and Connect to Social Care (pa-navigate.com)](pa-navigate.com)

3/7/2024
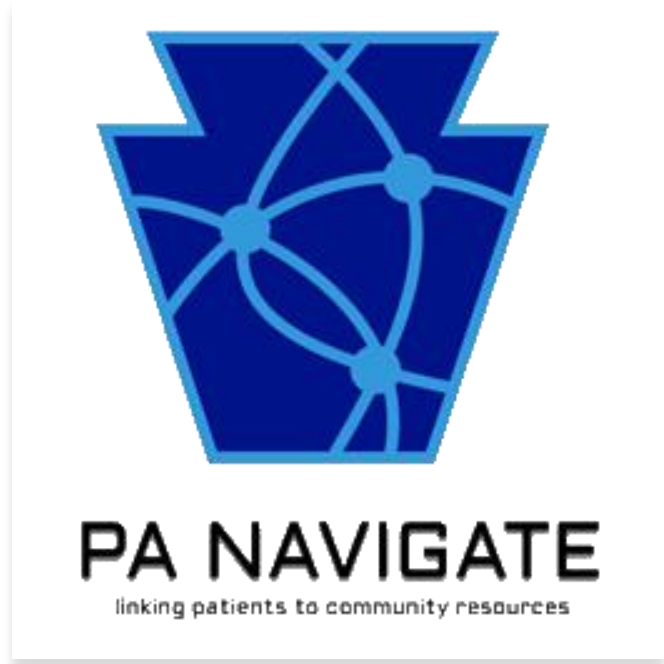
23

In January of 2024, a new tool was announced in PA. Anyone can use PA navigate.

"Shapiro Administration Launches PA Navigate, A New Online Tool to Better Connect Pennsylvanians with Food, Housing, Childcare and More
PA Navigate's primary goal is to boost communication between health care and social services to improve follow-through on referrals, as well as to act as a support finder for citizens."

PA Press Announcement,1/23/24
[PA Navigate by findhelp - Search and Connect to Social Care (pa-navigate.com)](pa-navigate.com)

We also set out to find out what families want across life domains.

In the 2023 survey, we wanted to also learn more about what families are needed in different areas of their lives.

We used the LifeCourse principle of life domains to create our questions. We asked one question focused on things in each life domain and asked people to choose as many as they needed information about. We hope that this will be helpful for everyone to know.

Holistic Focus Across Life Domains Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)
People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. Life domains are the different aspects and experiences of life that we all consider as we age and grow.
These include:
• Daily Life & Employment
• Community Living
• Safety & Security
• Healthy Living
• Social & Spirituality
• Advocacy and Engagement

Daily Life & Employment Topics

Daily Life
&
Employment

Employment
19%

Life skills
38%

School and other ways
to learn new things
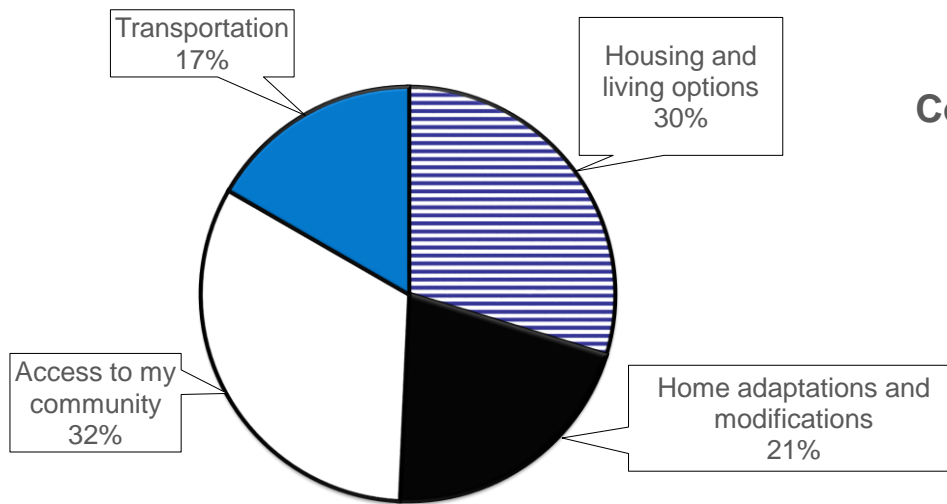13%

Volunteer opportunities
30%
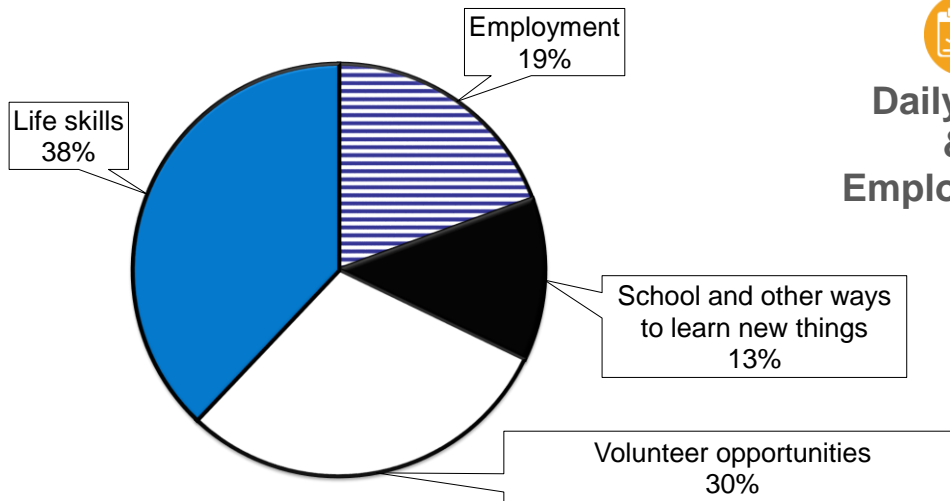
3/7/2024   25

Directions: Select as many items on this list of DAILY LIFE & EMPLOYMENT topics that you want to learn more about.

Answer	Percent(%)	Count(N)
Employment	19.39%	70
School and other ways to learn new things	12.74%	46
Volunteer opportunities	29.92%	108
Life skills (cooking, laundry, shopping, taking care of my body and my house, and other things that build independence)	37.95%	137
Total	100.00%	361

Directions: Select as many items on this list of COMMUNITY LIVING topics that you want to learn more about.

Answer	Percent(%)	Count(N)
Housing and living options (where I live, who I live with, how I live)	29.76%	125
Home adaptations and modifications (smart home technology and assistive technology, ramps, grab bars)	20.95%	88
Access to my community (know what's happening, have people go with me to an event, learn how to request accessible sidewalks or building entrances)	32.62%	137
Transportation (public transportation, make my vehicle accessible)	16.67%	70
Total	100.00%	420
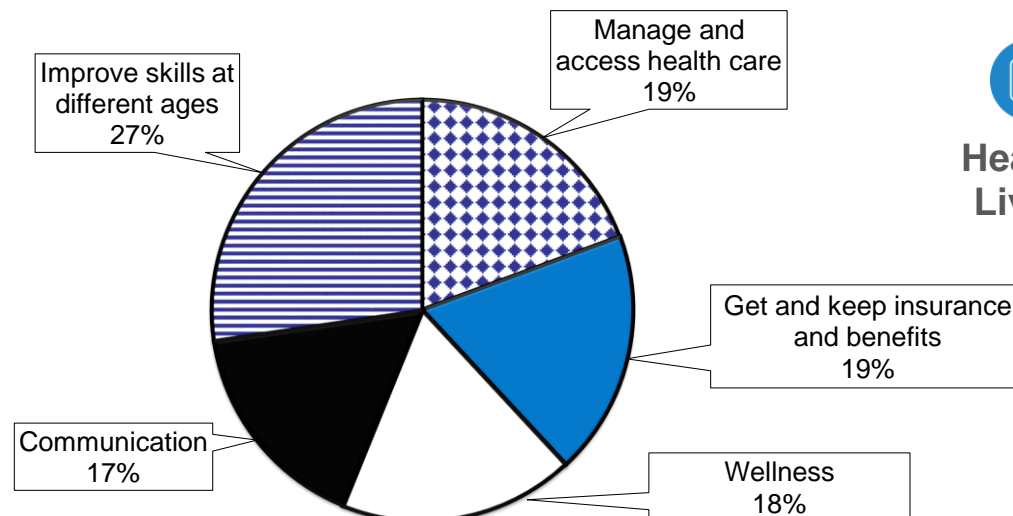
Directions: Select as many items on this list of HEALTHY LIVING topics that you want to learn more about.

Answer	Percent(%)	Count(N)
Manage and access health care (find a doctor, dentist or specialist, know what specialists I can see, find health care providers that understand my diagnoses and needs)	19.35%	90
Get and keep insurance and benefits (understand what to do, who to contact, fill out and return forms, understand what services I can have)	18.71%	87
Wellness (know about my needs like why and when I take medications and what my diagnosis means, self-care, exercise, nutrition, know about services that can help me)	18.06%	84
Communication (an iPad, adaptive equipment like hearing aids, learn American Sign Language, translation apps)	16.56%	77
Improve skills at different ages (speech,	27.31%	127

physical coordination, feeling and dealing
 with emotions, understand and
manage sexual health, social skills)
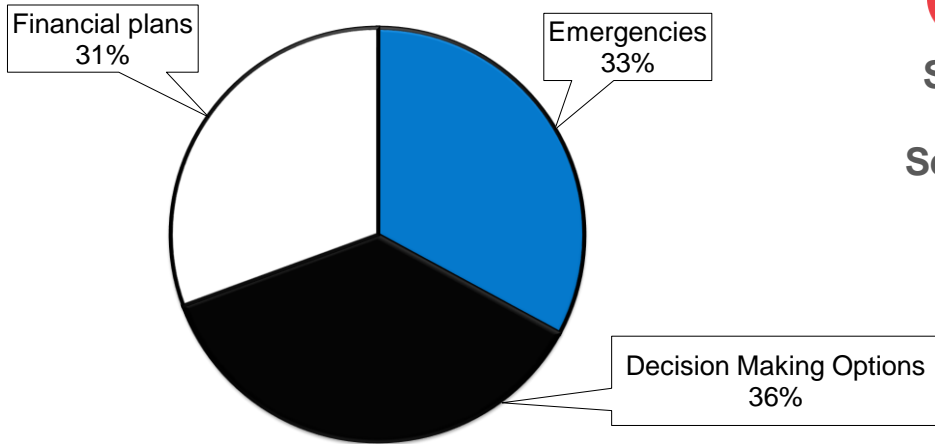
Total	100.00%	465

Directions: Select as many items on this list of SOCIAL & SPIRITUALITY topics that you want to learn more about.

Answer	Percent(%)	Count(N)
Well-being (how I feel about myself, know what I enjoy, know my strengths)	25.46%	83
Learn about healthy and safe relationships (in-person And online boundaries and social skills, dating and marriage, sexual relationships)	27.91%	91
Meet people in my community (building friendships, personal networks, neighbors, and people at my church or synagogue)	46.63%	152
Total	100.00%	326

Safety & Security Topics

Safety & Security

Financial plans 31%
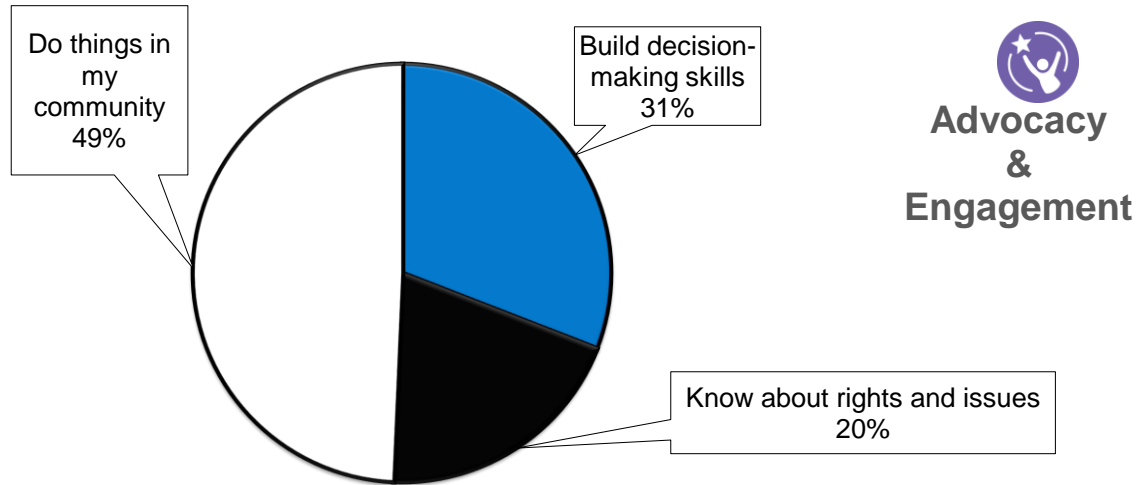
Emergencies 33%

Decision Making Options 36%

3/7/2024

Directions: Select as many items on this list of SAFETY & SECURITY topics that you want to learn more about.

Answer	Percent(%)	Count(N)
Emergencies (when to contact the police, helplines, poison control or others, being ready for weather-related disasters, plans for when a loved one dies, what to do if there is a fire, technology to contact someone when there is an emergency, what to do if I don't have things I need like medicine)	32.89%	100
Decision Making Options (Supported decision making, medical or financial power of attorney, Guardianship options like specified or full guardianship)	36.51%	111
Financial plans (have and use a bank account, life insurance, a burial plan, budgeting, special needs trust fund, having a representative payee)	30.59%	93
Total	100.00%	304

Directions: Select as many items on this list of ADVOCACY & ENGAGEMENT topics that you want to learn more about.

Answer	Percent(%)	Count(N)
Build decision-making skills (making choices, set goals, take responsibility, direct how I live)	30.89%	114
Know about rights and issues (being free from abuse, human rights, rights under regulations, Legal rights like seeing children or domestic violence, voting and civic rights)	19.78%	73
Do things in my community (clubs, sports, hobbies, going places, events, restaurants/businesses)	49.32%	182
Total	100.00%	369

What are the **most** important?

We noticed some things were most important to people.

Top 10

1. Do things in my community
2. Meet people in my community
3. Life skills
4. Access to my community
5. Improve skills at different ages
6. Housing and living options
7. Build decision-making skills
8. Decision Making Options
9. Volunteer opportunities
10. Emergencies

We can see across life domains, which things the most families wanted information about. We're sharing this information with you so that you can know what people are saying and so that you can play a role in improving supports to families.

The SC can also help you think about different ways to meet your needs.

THINGS YOU WOULD LIKE TO LEARN ABOUT	TOTAL	PERCENT
Do things in my community (clubs, sports, hobbies, going places, events, restaurants/businesses)	182	53%
Meet people in my community (building friendships, personal networks, neighbors, and people at my church or synagogue)	152	44%
Life skills (cooking, laundry, shopping, taking care of my body and my house, and other things that build independence)	137	40%
Access to my community (know what's happening, have people go with me to an event, learn how to request accessible sidewalks or building entrances)	137	40%
Improve skills at different ages	127	37%

(speech, physical coordination, feeling and dealing
with emotions, understand and manage
sexual health, social skills)

Housing and living options 125 36%
(where I live, who I live with, how I live)

Build decision-making skills 114 33%
(making choices, set goals, take responsibility,
direct how I live)

Decision Making Options 111 32%
(Supported decision making,
medical or financial power of attorney,
Guardianship options like specified or
full guardianship)

Volunteer opportunities 108 31%
Emergencies 100 29%
(when to contact the police, helplines,
poison control or others, being ready for
weather-related disasters, plans for when
a loved one dies, what to do if there is a fire,
technology to contact someone when there is an emergency,
what to do if I don't have things I need like medicine)

A Few Things Stood Out

pennsylvania
DEPARTMENT OF HUMAN SERVICES
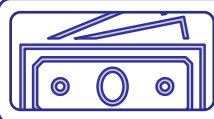
Financial Learning

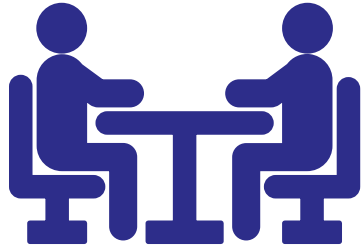Life Skills information, experiences, and opportunities

Community inclusion

Improve skills at different ages

Some of the top ten topics have similar themes.

Discussion: What people want information and support about

Why do you think these areas are important to people?

What can you do about it?

We found that it was helpful to talk about what we heard and to hear other people's ideas. We decided to share this information with you so that you can join in the conversation too.

# Why didn't people want information and support about…?

Healthy Relationships	Rights Issues

When the Supporting Families Statewide Leadership Team discussed the responses to the survey, we wondered why these topics were not selected by more families. So, we talked about it and we think that:

- People may not think that healthy relationship information is important due to undervaluing people due to their disabilities.
- People may not realize how important rights issues are and how knowing more can help them.

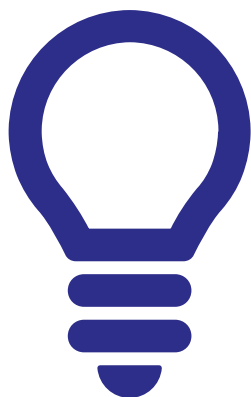Discussion: What people
didn't want information and
support about
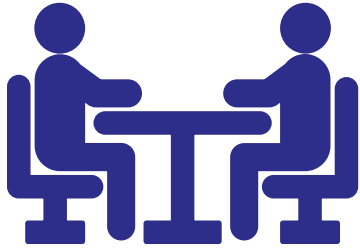
Why do you think people
didn't select these areas or
other areas?

What can you do about it?

What are your thoughts about why more families didn't select healthy relationships or rights issues? Are there things that surprise you that you wonder why more families did not select?
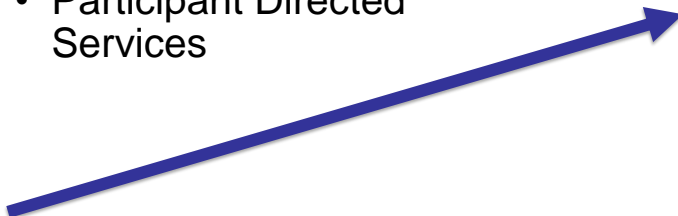
A few suggestions

The Supporting Families State Leadership Team has a few suggestions based on our review of the survey responses.

From the Supporting Families State Team

- Share information
  - Ask people how
  - Ask people what
- Integrated employment opportunities
- Participant Directed Services

Families and individuals receive information and support when and how they need it.

To reach the vision that families and individuals receive information and support when and how they need it:

- Ask people how they want to receive information and support
- Ask people if they would like information when an issue arises in discussions and events
- Help people explore integrated employment opportunities
- Help people use Participant Directed Services to have the needed supports to engage in integrated activities and work

pennsylvania
DEPARTMENT OF HUMAN SERVICES

"Supporting families means that **resources flow to those who need** them the most, **when they need them** the most, **with an array of desirable options** for support."

- Wingspread report, 2012, page 3

Thank you for all that you have done and will do to try to make this a reality for all people!