Review of Oregon’s ISP planning process
July 30, 2019 Webinar
House keeping

- Participants will be muted during the presentation
- You can ask questions anonymously via chat
- We’ll respond to questions during the last 30 minutes and answer as many as we can!
- After the survey, we’ll email you a short survey.
- Later, we’ll email registered participants a link to the report, presentation and webinar recording in both English and Spanish
Report overview

- Background info
- Part 1: Focus groups
- Part 2: State interviews
- Questions and answers
Background to LifeCourse and the ISP redesign project
Background to LifeCourse and the ISP redesign project
What is Charting the LifeCourse?

Guiding Framework:
- Guides thinking and problem-solving

Practices:
- Specific Area (action, policy, procedure) to enhance or change

Tools:
- Planning & Problem-solving Worksheets
Part 1: Focus groups

Methods

Participants

Findings
Focus group methods

- Identified communities
- Developed questions
- Published a survey
- Convened focus groups
- Conducted outreach
- Hired facilitators
- Analyzed data
- Compiled findings
Focus group facilitators
Family member questions

1. What about the service planning process is useful to you/your son or daughter?

2. What should be different about the service planning process to make it more helpful or useful to you/your son or daughter?
Family member questions

3. How might your support plan be more meaningful or helpful to your/your son or daughter’s daily life?

4. What changes would you recommend to improve the process so that people can be a part of their community and have a good life?

5. Of all the things we talked about, what is most important to you?
Self-advocate questions

1. What is a good life?

2. How does your plan help you get there (to your good life)?

3. What helps you be in control of your plan?

4. What gets in the way of you being in control of your plan?

5. Overall, what is most important about your plan?

What I want

What I don’t want
Focus group participants

<table>
<thead>
<tr>
<th>Area</th>
<th>Family members</th>
<th>Self-advocates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eugene</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>Medford</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Klamath Falls</td>
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<td>4</td>
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<tr>
<td>Pendleton</td>
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<td>1</td>
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<tr>
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<td>10</td>
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<tr>
<td>Seaside</td>
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<td>1</td>
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<td>Portland</td>
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<td>6</td>
</tr>
<tr>
<td>OCDD members</td>
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<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>40</strong></td>
<td><strong>63</strong></td>
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Findings

1. Many participants report they do not experience a person-centered ISP planning process.

2. Many families do not understand the difference between the needs assessment and the ISP planning process.

3. Clear and comprehensive information about the planning process, available services and community resources is not available.
Findings

4. Adults want to be in control of their meetings, set their own goals and make their own decisions.

5. People want meaningful goals and related supports to reach their goals.

6. People want equitable access to a wide range of supports – not just service hours.

7. Good relationships with case managers is key to the ISP planning process.
1. A person-centered process

People want to experience a person-centered ISP planning process that is:

- Unique to the person
- Focused on strengths and abilities
- Based on the person’s choices and preferences
- Includes input from people close to the person
- Identifies services, supports and community connections that will help a person reach their goals and vision for a good life
Positive experiences – what we want

“My case manager cares about what I want.”

“We have a good conversation about the future and the supports needed to achieve desired goals.”

“My son is the primary part of the meeting.”
Challenges – what we don’t want

• Participants lack enough information to participate in a meaningful way.
• Poor understanding of decisions being made.
• Goals are not meaningful to the person.
• Supports do not line up with the person’s goals.

  – “I want help to learn how to do things for myself, to be more independent.”
2. Confusion about assessment & planning

Challenges – what we don’t want

• While most adults report they understand the planning process, many family members do not.
• Especially parents of children under age 18.

“What is the difference between the assessment and the service plan? Do they fill out documentation while they are having conversations?”

“I don’t feel like I have a planning process.”
3. Lack of clear, comprehensive info

Challenges – what we don’t want

- Overall, most participants report little access to information that would help them understand and participate in a meaningful way.

“We need to know how to navigate these processes and systems and no one is doing trainings to support this.”

“When you don’t understand it, you don’t know what you are answering or what can happen.”
Positive experiences – what we want

“I had a great case manager who explained the whole process to me before the meeting... She even sent me all the materials and what to think about before the meeting, so I felt prepared.”
Participants want information about...

- The ISP and the planning process
- The needs assessment and how it informs the ISP
- The case manager role
- What to expect during planning meetings
- Rights and responsibilities
- How to practice self-determination or support someone to do so
- How to prepare for their meetings
- Available services and community resources to meet their needs and address ISP goals
Additionally, adults want to know...

- What each section of their plan means
- How to practice self-determination
- What they want to say before their meeting
- Who to invite
- What services or resources are available and what their options are
- How to file a complaint
- Who to call when things change
4. Being “the boss” of one’s own life

What we want

• Adults are the boss of their plans and their own lives.
• Adults are in control and make their own decisions with support, as needed.

• “It’s important to make my own decisions.”
• “No one can tell me what I can and can’t do.”
• “We want to talk about what we need, not what they need.”
What case managers can do...

- Listen to the person
- Treat the person with respect
- Help the person to say what they want or need
- Help the person understand their rights
- Do not speak for the person without permission
- Don’t let others to talk for the person without permission
- Make time for the person to understand if meeting is going too fast
What case managers can do...

• Support people to lead all or some of their meetings, as desired.
• Help people to “have a voice” in how their meetings are run.
• Help people make their own decisions, as needed.
• Make sure the person’s voice is heard, especially when team members disagree.
5. Meaningful goals and related supports

Challenges – what we don’t want

• Goals are not meaningful
• Supports are not directly related to helping a person reach their goals
• Self-advocates and families not informed about what supports or resources are available and what to ask for.
Challenges – what we don’t want

• Not feeling empowered to ask for what they want
• Not being informed about what services or community resources are available to meet their needs
• Not having meaningful planning conversations
• Lack of responsiveness and follow through from case managers
• Heavy case loads and paperwork burden
Positive experiences – what we want

“I didn’t know what was available and the case manager was able to say, you need this, or this is where you need to go for that. A lot of stuff came up that wouldn’t have if I was just filling out a questionnaire or if she hadn’t spent 1½ hours with us.”

“My plan provides enough support to help me reach my goals.”
6. Equitable access to a wide range of supports

Challenges – what we don’t want

• Limited support for healthy relationships and to connect to one’s community
• No information about what services are available
• Long waits for assistive technology, home modifications and behavioral supports
• Limited access to skills training, employment services, transportation and community resources

“I want to have friends and romantic relationships but my staff are not comfortable supporting this.”

“I want to get to know my community.”

“There were so many hoops that we couldn’t ever get what we needed... we have been waiting for two years.”

“The case manager hasn’t figured out how to access the assistive communication device, so our planning process has been useless.”
Challenges – what we don’t want

• Language barriers
• Emphasis on paid service hours provided by PSWs/DSPs
• Difficult to find and keep PSWs/DSPs, especially in underserved communities
• Hard to find qualified PSWs/DSPs to provide specific support to increase independence or help people develop relationships with others in the community
• High turnover rate

“I was not able to communicate until they hired a case manager who spoke Spanish.”

“We need someone to take him in community and teach safety and life skills. We have not been able to find that.”

“The social piece is only with my son’s paid support person. This is not a natural friendship with someone he chooses in community.”
7. Good relationships with case managers

Challenges – what we don’t want

• “Unless I call and say we are in crisis, we aren’t receiving ideas.”

• “Case manager turnover is too high, and makes it so that we start all over each time.”

• “I love the case manager, but they forget to follow up.”

• “It seems like keeping paperwork up to date is the most important thing.”

• “The ISP has a way of making someone feel like just a file in the cabinet.”
Positive experiences – what we want

Positive experiences – What we want

• Responsiveness to emails and phone calls
  – “I can contact my case manager and ask for help if I need it.”

• Follow through on tasks

• Spending time to get to the know the person/family

• Individualized support to plan or access services and community resources
  – “My case manager is always sending us little things that are going on in the community... she is trying to help us find inclusive activities for my son to get involved in.”
Part 2: State interviews

Methods
Participants
Findings
State interview methods

- Identified CoP states
- Developed questions
- Convened interviews
- Compiled findings
- Clarified information
- Analyzed data
Questions

1. What initiatives is the Supporting Families CoP focused on in your state?
2. What problems with the service planning process are you addressing?
3. How have you embedded the LCF and tools into the service planning process?
4. What parts of the process, forms, etc. have changed?
5. How have you balanced Medicaid requirements with making the service planning process person-centered?
Questions

6. What does the planning process look like?
7. What skills and training are critical to CMs and others working in the DD service system? Who provides the training? What is the content?
8. What training on the planning process is available to self-advocates and family members? Who provides the training? What is the content?
9. What have you learned?
10. What advice would you give to other states using the LCF to improve the planning process?
CONNETICUT

6 years in CoP
DDS Director of Family Support Strategies and Advocacy, Robin Wood

INDIANA

3 years in CoP
DDRS Deputy Director, Julie Reynolds
DD Council Director, Christine Dahlberg and Deputy Director, Chad Crowe

DISTRICT OF COLUMBIA

6 years in CoP
DD Council Director, Alison Whyte
DDS Director of Quality and Improvement, Erin Leveton
Findings

• Connecticut, Indiana and Washington DC used LifeCourse to improve the ISP planning process

• LifeCourse helps states meet Medicaid requirements for person-centered planning (PCP)

• Each state used specific strategies to train a wide range of stakeholders

• Lessons learned contribute to the strategies used in Oregon
Person-centered planning in Medicaid rule

- Driven by the person
- Includes people chosen by the person
- Info and support to help the person direct the process
- Meetings are timely and convenient to the person
- Culturally responsive and accessible
- Problem solving when there are disagreements
- Offers choices of services, supports and providers
- Reflects personal preferences
- Updated as needs change
- Identifies strengths, needs and desired outcomes for a good life
- May include self-directed services
- Goals related to relationships, community participation, employment, income and saving, healthcare and wellness, education, etc.
- Says how to address risks
- Signed by person and service providers
LifeCourse helps states meet Medicaid requirements
## Improvements to the ISP process

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<thead>
<tr>
<th>CONNECTICUT</th>
<th>INDIANA</th>
<th>WASHINGTON DC</th>
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<tbody>
<tr>
<td><strong>New ISP form</strong> includes One-Page Profile, Trajectory and questions by life domain</td>
<td><strong>New Interview Guide</strong> for service intake meeting to add integrated supports conversation</td>
<td><strong>New Front Door Tool</strong> for service intake meeting includes Trajectory, Integrated Supports Star, employment questions and warm referrals to other agencies/resources</td>
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<tr>
<td><strong>New Pre-ISP meeting</strong> to complete One-Page Profile and Trajectory</td>
<td><strong>New PCISP form</strong> includes like and admire about me, strengths, vision, life stages and life domains</td>
<td><strong>New joint VR-DD service intake</strong> process to speed up referrals to VR</td>
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<td><strong>New LCF webpages</strong> on state website for families with LCF tools, information about how to use them and where to go for training</td>
<td><strong>New IT system</strong> makes plan electronic; “move focus from paper to people”</td>
<td><strong>New ISP form</strong> includes person-centered thinking tools, Relationship Map, Trajectory, Integrated Supports Star</td>
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<td>DDS Helpline staff refer families to LCF webpages and school districts that provide support to use LCF tools</td>
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<td><strong>New six-month review</strong> to align goals with person’s vision for a good life</td>
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Trainings for stakeholders

CONNECTICUT

• Ambassador trainings for 90 case managers, Spanish speakers, providers, family advocates, educators and VR counselors
• Person-Centered Planning trainings for 400 case managers
• Individual Planning Buddy training for self-advocates
• Trainings on how to use the LifeCourse tools for all stakeholders provided by Ambassadors
• LifeCourse brochures and webpages organized by life domains for parents and guardians
Trainings for stakeholders

INDIANA

• Trainings on how to use the LifeCourse tools for 600 case managers, family members, self-advocates and service providers

• Trainings on planning for employment using LifeCourse tools
Trainings for stakeholders

WASHINGTON DC

- Two-day Person-Centered Planning training required for all DDS staff and case managers within first year of employment
- Families Planning Together for family members
- Employment Toolkit for family members
- People Planning Together with a focus on employment for self-advocates
Lessons learned...

- DD state agency and DD Council partnership supports effective systems and community level change
- Engage wide range of stakeholders as early as possible to gather input, create buy in and develop champions
- Clear and frequent communication about systems changes is important – especially for self-advocates and families
- Train a wide range of stakeholders to use the tools and to be LifeCourse Ambassadors to mentor, support and train others
- Ensure that self-advocates and families have access to comprehensive and accessible information about how to use integrated supports to pursue a good life
Next steps... DD system efforts

Vision Advisory Group
Developed consensus and buy-in that resulted in LifeCourse being included in the ODDS strategic plan

Compass project

ISP process redesign

Blueprint project

Who
ODDS, OCDD, DD Coalition, Stakeholders identified the right participants for each

What’s Next
• Embedding LifeCourse in all levels of ODDS
• Including cultural agility and service equity
• Finalizing ISP process redesign and rollout
• Ongoing training to all stakeholders
Next steps... Grassroots efforts

- Expand engagement with OSAC & Family Organizations
- Expand training opportunities
Questions and answers