A Checklist for Person Centered Information Gathering and ISP Development

Developed by
Smull, Bourne, & Allen • 2008
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A Check List for Information Gathering

Stage 1 - Thinking about what you want to learn and how to learn it

Before you begin to gather information for a plan with anyone you should learn what the person and those around them want the plan to accomplish. If you are working with someone to develop a plan that is the annual ISP make sure you are helping people to look at what is going on in the person’s life and discovering what needs to change and what needs to stay the same. Service plans have to conform to the rules but they do not have to be empty rituals that do not help the person move forward with their life.

Make sure that you are planning in partnership, that you are planning smarter. Look to see how the person can best participate in each phase. How about family members? Are there others in the person’s life who can assist? Remember that the more you support others in developing a good plan the more likely it will be used and acted on.

Have you answered the following questions?
- What does the plan need to accomplish?
- What results does the person want in his or her life, after this plan is implemented?
- Who else needs to participate/agree so that the plan is implemented?

Learning who to talk to
- Do a simple “relationship map” with the person (if the person does not communicate with words fill it out as you think they would, ask others who are also close to the person if they agree with your information)
- Start gathering information from the people closest to the person.

Before you gather information ask -
- How can the person with whom you are planning best participate in the development of the plan?
  o Are there parts of the process that they can do or support?
- Are there family members who can take a lead role in gathering information or in putting the information into the plan?
- Are there people who are not related but who know and care about the person? If yes
  o How will you gather information from those people?
- How do you plan to make sure that the process feels respectful to the person with whom you are planning?
- Who knows what it takes for the person to be happy?
- Who best understands any issues of health or safety?
- What is the best way to gather information from the people who know the person best?
Develop an information gathering strategy from the answers to the above questions. Determine which questions you will ask of which people and at what time? Use a chart to keep track of who will provide what information.

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<th>Who Should be contacted?</th>
<th>What questions should we ask?</th>
<th>Who will talk with them and when?</th>
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Stage 2 - Gathering information

Using what you learned in the previous section, gather information using either conversations/meetings face to face or phone calls. We know that the least effective method of assessment and information gathering is to mail out blank ISP pages or forms and ask people to complete them and return them to you. Be sure you have had conversations using the guidelines listed below. Record information from conversations on either the conversation packs found at www.elpnet.net, or the handouts from Facilitator Training. Look at what you have and see if you have information recorded in several of the following areas:

Learning from the person:
- Great things about you
- What you like to do (favorite things/things you don’t like to do)
- The best/worst week day information sheets
- The best/worst weekend information sheets
- The positive rituals survey

Learning from those who know the person:
- Learning who to listen to: Using “Talking with people who know and care: an individual interview”
- The “unlimited power” questions;
- Two minute drill;
- Great things about this person;
- What he or she likes to do (favorite things/things he or she doesn't like to do);
- The best/worst week day information sheets;
- The best/worst weekend information sheets;
- The positive rituals survey.
- Additional Health and Safety Rituals or Routines
- The communication chart (when the person does not use words to talk or communicates in other ways)

Learning from other information gathered about the person:
- Is there information that a regulatory requirement dictates must be gathered? If so, who will provide it to the ISP facilitator?
- Does an agency policy or funding source policy require certain administrative information be included in the person’s plan in order to provide funding for services? If so, have you collected it?
☐ Assessment information collected by a provider to complete the Health and Safety focus areas or the Functional Areas.
☐ Previous Notes/Medical History information regarding contacts/medical appointments, follow up, etc.
☐ Quarterly reports indicating Health or Safety issues addressed during the year.
☐ Information reported through the Incident Management system of your state, which may be necessary to plan for the person's health or safety during the upcoming year.
☐ Other information required by your state administrative agencies
Stage 3 – Developing a draft first plan

After you have completed some parts of stage 2, you will be ready to start this stage.

Write a first draft based on what you have learned.

- Look at the answers to the “like the most”, “admire the most”, and “great things about you” questions and see which answers should be in the section called What Others Admire About . . .
- Look at the “people” or relationship map and see who is important to the person and how important.
- Look at the favorite things, best day/worst day, and positive rituals information and ask what that tells you about what is important to the person and how important each item is.
- Look at the answers to the “unlimited power” questions and ask what that tells you about what/who should be present or absent in the person’s life and how important those things/activities/people are.
- Look for agreement among the people that you interviewed. Where there is agreement you can feel more comfortable that the information is probably accurate.
- Who else do you need to talk to/get information from? What is the easiest and best way to get that information
- What questions do you still have? What issues still need to be resolved? Make a list of the things to be figured out.

Did you remember to:

- Separate what is important for the person from what is important to the person?
- Include what needs to be absent from the person’s life, what they dislike?
- Include all of the details of rituals/routines, only if the person needs a lot of assistance in getting things done and can’t tell people how they want it to happen.
- See if the plan has information that the person does not want everyone to know. If it does, you may need to develop “public” and “private” sections of the plan. Include critical health information if the person will be supported by people other than family members?
Guidelines to use in writing each section of the plan

Going from first draft to first plan
When you have a draft you think meets first plan criteria ask someone you are comfortable with to read the plan to see how well it communicates (be sure to follow all confidentiality requirements of your agency). Ask the reader to share all of his/her questions. This will help you with clarity. Don’t forget to review your draft with the person. It is very important that the plan respectfully convey the information necessary so that people who provide support understand what matters the most to the person. It is also important that the plan convey how to achieve that while also balancing health, safety and issues necessary to be valued by the community. This requires language that is respectful and demonstrates the person’s gifts and talents, yet is easily understood by the reader.

General rules for your next draft are:
- Use complete thoughts; short, concise sentences are better than single phrases.
- Use common, everyday language rather than the terms and abbreviations used by government and community agencies that support people; (avoid jargon)
- Make sure that each item listed has enough detail and/or enough examples that someone newly present in the person’s life would understand what was meant;
- There are no long “laundry lists” of items, those that go together are grouped together, with a space between groups; and
- Where there are 4 or more things grouped together there is a topic statement followed by the group of items with bullets.

In the administrative section (or cover page) the reader should learn:
- Whose plan is it;
- When it was done;
- Who the support coordinator is
- Where the person lives;
- Who the person lives with
- Anything else that is required by your local administrative entity.

Introduction – What Others Like and Admire about the person: should list what other people like and admire about the person and:
- It should list things that we might like or admire about anyone of roughly the same age.
- It should not include things that we only say about people who need support or is “faint praise”.
- It should use the same type of language we use to introduce new friends or neighbors.
Where there are more than 6 or so items listed, related items should be grouped to make it more likely that they all will be read.

**What Others Need to Know or do to Support**, this section of the plan clearly describes what people who provide support are expected to do so that the person is likely to have more good days, balanced with what is important for them. Where there are four or more items that are similar, use one statement to introduce the 'theme' followed by bullets with the details. Separate distinct thoughts. In this section, the reader learns what others need to know or do:
- So that the person has what is important to him or her; and
- There is a good balance between what is important to and what is important for the person.
- This section of the plan is written with sufficient detail so that those responsible for providing the support will get it right.
- It includes directions on preferences and approach that are not found otherwise in the ISP

"Characteristics of People who Best Support" informs the reader about who or what type of people should work with the person.
- What are the characteristics that you should look for? For example, Katherine's section includes: "enjoys being silly; and, comfortable with sharing personal space." These are things that a support person must "come with" and cannot be "trained to do". For the ISP you will need to include this information in the section titled What people Should Know and Do to support.

**What is important to the person**, this section describes what the person perceives as being important to him or her. This section represents the person's perspective.
- It must not include items that others think should be important to the person. (These are things that are important for the person and may be used in the next "support" section.)
- It should only include those things that the person "tells" us are important (with words or behavior).
- These should include what the person views as important in —
  - Relationships,
  - Things to do
  - Places to be
  - Rituals and routines
  - Rhythm or pace of life
  - Items to have available
  - Other things which are likely to contribute to the presence of more good days than bad days in the person’s life.
- They should be sorted by those that are the most important and those that are important (but not critical).
Desired Activities these include things to do from the person’s perspective.
- They should include activities the person would like to try, but may not have had a chance to try yet
- They should include activities that the person enjoys doing and would like to do on a regular basis
- This should also include things to do that the person has expressed an interest in and the team has not figured out how to make it happen.

To do this requires 2 separate skills. Those participating need to be able to look at the current situation from the perspectives of the person, those paid to support and (where their perspective is different) family members. The second skill is the ability to tease a situation apart so that both what makes sense about the current situation and what does not make sense about the current situation is clearly described from each perspective.

It is helpful if the “what is and is not working” analysis occurs in a focused manner. If people give general answers, then ask the questions specifically about:
- Where the person lives
- Who lives with the person
- What the person does for fun
- What the person does with his/her days
- The amount of control the person has in his/her life
A few additional tips on using What is Working/Not Working as a tool for the team to strategize.
  o This is a tool for negotiating differences. The 3 rules of negotiating include
    o Everyone must feel listened to
    o Start with common ground
    o Remain unconditionally constructive – “How Can We.....”
  o Everything in life has a few upsides and a few downsides; it is the balance between the two as well as the weight of each issue that matters.
  o In addition, the person’s perspective should come either directly from him or her, or else from only those people who know him or her the best.
  o It is NOT a method to change people’s opinions, or to even get everyone to agree with one opinion. It is a method to give everyone a chance to have their different perspectives heard.
  o It is NOT a list of “What WOULD make sense IF.....” It is to be a true picture of CURRENT REALITY for the person’s life.
  o Where there is agreement, you have an agenda to build your action plan (start with common ground!)
  o Using shorthand or one word descriptions is confusing and increases the likelihood support staff will act in the wrong manner. For example, just recording the word “work” under What Makes Sense from the person’s
perspective could mean many things. It is much more focused and helpful to write “having work that he is paid to do”.

Finally there needs to be a description of what is going to be done to maintain those things that do make sense, address those that do not make sense, and answer the questions in the “things to figure out” section. This description of activities is best addressed through the Action Plan section addressed later in this guideline. Using this information is a good bridge to Outcomes Development.

The sections of the ISP covering Medical Information should include:

- Information about the health professionals involved in the person’s life, and recent health appointments.
- Information about medication and side effects that the person has experienced or could experience.
- Information about allergies, current and past diagnoses, and particular health concerns and how they are addressed.

**The separate sections on Health and Safety Focus Areas must include specific instructions regarding what the person is able to do for themselves in the specific area. Include instructions regarding how best a person can be supported by others within this area, and any assistance they will need from others.**

**Be sure to pay attention to:**

- **Always start with those things the person is able to do for him or herself; the talents and abilities the person has in the specific area.**
- Special instructions about how a person swallows, or the help they need to avoid choking if this applies, or how a person needs to be positioned.
- Any safety issues that the people who provide support must know about. These should include a clear description of the degree to which the person can keep him/her self safe, and the type of support they need from others to stay safe.
- Any other issues that people who will provide support (paid or unpaid) should know about in order to minimize the risks towards the person’s health and safety.
- Include in this information general safety information, fire safety, stranger awareness, traffic safety, cooking and appliance use, conveying information about the person’s identity, and awareness or understanding of materials or items in the home or outside that may pose a risk or threat.
On-going learning and using what has been learned

Continuing the learning and recording what you learn -
Who else needs to contribute? What is the best and easiest way to get their contribution? Some of the ways listed below may work. Remember that you can use just one of them or combine them –

- Continue to interview people
- Send some of the information gathering pages from the manual
- Send parts of the draft plan for them to write on
- Have an information gathering party

How are you going to record the on-going learning? People change and our understanding of them deepens over time. You need to have easy ways to record this learning or it will be lost. Think about who will be doing the learning and what way(s) of recording it will be easiest for them. Look at the ways that are listed below and think about what will work best for you.

- As you learn new information, write it down in the white space on the right side of the plan. Write down questions on the right side of the plan, where you think there is learning to do. Make multiple copies of the plan and ask those involved to write their impressions on the plan. Gather these copies as makes sense and enter the learning on the typed side.
- Get copies of the plan to the people who will be doing the learning, with questions written on them. Interview them as you write notes and transcribe it on to the plan.
- Have periodic gatherings of those people who care about the person and ask them what they have learned. Take notes and transcribe the learning onto the plan.

Using the plan (acting on what was learned)
The purpose of developing a plan is to help the person move toward the life that they want while addressing any issues of health or safety. For people who are not getting paid services this process can be very informal.

- For people who receive paid services, the process of planning and review often have federal and state requirements. While essential lifestyle plans can be (and are) written to meet these requirements, some changes and additions are usually needed. These are addressed in the ISP document.
- Every agency also has its own planning format and develops and updates the plans through a formal meeting process. However, regardless of the process, any gathering of people who are looking at the future should seek to answer the following questions. Since the last time we got together -
  - What have we tried?
  - What have we learned?
  - What else might we try?
  - What else do we need to learn?
What do we need to do next?
In many instances there needs to be a process that helps people summarize the learning and then go to a description of how they are going to act on what they have learned (recorded in the outcome action section of the plan). The methods used during this process should be recorded in the “how will we know progress is being made?” section of the Action Plan. It may be necessary to repeat the What’s Working and Not Working Section of the plan, after reviewing what has been tried. This information is then compared with Outcomes and Actions, and can be used to document the progress that has been made on the outcomes.

For sample plans, additional Conversation Packets, or other materials to assist you with developing person centered approach toward developing ISP’s, please visit the website: www.elpnet.net.
Based on the work of

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