

FAMILY AND FRIENDS MANUAL



EASA Center for Excellence



SCHOOL OF
PUBLIC HEALTH



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The information provided in this manual is intended as a guide for general educational and informational purposes only. This manual is not designed to replace professional medical advice, assessment, diagnosis, or treatment. Services with EASA are individualized based on each person's unique situation. This manual is not intended to replace clinical decisions made by local mental health center staff providing EASA services. Any decisions regarding diagnosis, treatment and/or provision of care for any individual in EASA are made by local community mental health center staff providing EASA services. Always seek the advice of a qualified health care provider with any questions you may have regarding a medical condition.



SECTION 1

GETTING STARTED: ORIENTATION TO EASA



Welcome to EASA for Family Members & Friends: What to You Need to Know

In the following pages you will find information about EASA that will be helpful to you throughout your time in the program. In it you will find:

- Information about EASA's philosophy and approach
- Understanding of the structure of EASA teams and the EASA Center for Excellence
- EASA guidelines for families
- What to expect from EASA, including your role in the assessment and treatment process
- Information about confidentiality and protected health information
- Tips for how to best communicate with your EASA team and answers to common questions
- Additional resources for family members and friends



This manual is written for you: the family members, friends, and loved ones of EASA participants. The terms used in this manual referring to family, friends, and/or loved ones mean any individuals that are important in your young person's life, for example, grandparents, siblings, friends, aunts, uncles, cousins, clergy, coaches, teachers, healers, partners, mentors, or roommates.

Here at EASA, we believe that the family, friends, and loved ones of our young people are vital in supporting their growth and aiding in their self-discovery.

Right now, you may be feeling many different things, including feeling exhausted, hopeful, scared, and/or overwhelmed. No matter how you are feeling, know that EASA is glad to have you and your involvement is a very important part of your young person's experience.

It is important for you to know that your EASA team is here for you. The goal of EASA is to offer the best support and services for you and your family through this time. This manual is designed for you. We hope that you will find it a useful reference throughout your time in EASA, as well as once your young person graduates from EASA.



The Early Assessment and Support Alliance (EASA) is a statewide network of programs providing early intervention for youth and young adults ages 12-25 who are at-risk for developing psychosis (often called psychosis risk syndrome) or those who are experiencing early symptoms of psychosis (often called first episode psychosis). The terms psychosis risk syndrome and first episode psychosis are used to describe a range of experiences that young people who receive EASA services may have already had or those that they may be currently experiencing.

EASA programs are provided by local community mental health centers and follow a common set of practice guidelines. These guidelines can be found on the EASA website at <http://www.easacommunity.org/PDF/EASA-practice-guidelines-2013.pdf> or you can ask any EASA team member for a paper copy. These guidelines are based on international early psychosis standards of practice.

Visit the EASA website at www.easacommunity.org for additional resources and information, including videos and handouts for family members and participants.



EASA offers specialized assessment, treatment, and support for both the individual and their family during a two-year period. In addition to a focus on understanding and treating your young person's situation, EASA provides education and support for your family so that you can help your young person recover and continue to progress into adulthood. At any point in time, there are about 400 Oregon families involved with EASA and many more who have graduated from EASA programs across the state. You are not alone!

The information in this manual is intended to be general enough to give information and education about these experiences, however, not all of the information may apply to your young person and their specific situation. The information is designed to be referenced throughout your time in EASA, as well as after your young person graduates from the program as needed for resources and support.



EASA Phases of Care

EASA services will look different for each young person and their family based on their needs, strengths, and goals. However, the following five phases of care are a general guide for what EASA services look like during the two year EASA service period and after graduation from EASA. Treatment in EASA is individualized and the amount of time each young person spends in these phases of care varies, although each phase (other than the post-graduation phase) typically lasts approximately 6 months.

In the assessment and stabilization phase the EASA team will:

- ✓ Provide outreach to the individual and family/primary support system
- ✓ Get to know the individual and family/primary support system
- ✓ Provide comprehensive assessment
- ✓ Assist with completion of recommended medical tests (as soon as possible!)
- ✓ Begin treatment for identified medical conditions, including psychosis risk syndrome, psychosis and alcohol/drug use
- ✓ Identify strengths, resources, needs and goals
- ✓ Begin joining sessions to engage in multi-family group process
- ✓ Stabilize the situation: symptoms, economic situation, housing, relationships, school, work, etc.
- ✓ Provide support and education to the individual and family/primary support system
- ✓ Provide opportunities for peer involvement, social connections, physical activity, etc.
- ✓ Assess need for ongoing services from EASA

In the adaptation phase the EASA team and young person/family will:

- ✓ Provide more extensive education to the individual and family
- ✓ Continue treatment
- ✓ Address adaptation issues
- ✓ Refine and test the relapse prevention/wellness plan
- ✓ Engage young person in alcohol and/or drug treatment if needed
- ✓ Continue multi-family group or single-family sessions
- ✓ Move forward proactively on living, education, and/or vocational goals
- ✓ Identify and establish necessary accommodations as needed at work or school
- ✓ Identify and develop stable long-term economic and social support
- ✓ Provide opportunities for peer involvement, social connections, physical activity, etc.



In the consolidation phase the EASA team and young person/family will:

- ✓ Continue multi-family group or single family sessions, continue with vocational and educational support, and individual treatment
- ✓ Continue to support young person in working toward personal goals
- ✓ Test and refine relapse prevention/wellness plan

In the transition phase the young person and family will:

- ✓ Maintain contact with EASA Team
- ✓ Continue multi-family group or single-family sessions
- ✓ Participate in individual treatment, as well as group opportunities
- ✓ Establish ongoing treatment relationship with new providers and refine recovery plan

In the post-graduation phase the young person and family will:

- ✓ Continue multi-family group (in some situations—ask your EASA team about this)
- ✓ Continue with ongoing providers
- ✓ Be invited to participate in EASA events and mentoring
- ✓ Be invited to participate in EASA planning/development activities
- ✓ Engage in periodic check-ins and problem solving with EASA team members as needed.



Getting Started: EASA Orientation Checklist

Meet the team

Your EASA team should provide you with a list of everyone on the team and what they offer, along with their phone numbers/emails and how to reach them. You are encouraged to meet everyone on the team when you are ready, and should know that each of these individuals is available to talk to you. If you do not live in the same area of Oregon as your young person, or if you live out of state, the EASA team can still communicate with you by phone and give you resources and information (**See Section on Confidentiality, Releases of Information, Informed Consent, HIPAA, and Rights**)

My EASA team members: 

Name/Title

Phone Number:

Email Address:

Notes:



Make sure you have a 24-hour crisis number and a crisis plan.

24 Hour Crisis Number:



The best thing to do is to work with your EASA team from the very beginning to address possible crisis situations and to make sure that you have a very specific written plan with at least one, but preferably two, back-up plans. To begin with, you want to create a safe and healthy environment. Work with your EASA team to determine specific situations where you may need to call the 24-hour crisis line and what to say when you call. See **Appendix B** for a copy of a crisis plan.

The crisis plan may address:

- What you will do if symptoms get worse
- What you will do in case of family conflict
- Depending on the situation, your plan may also address what to do in case of escalating behavior due to alcohol/drug use, victimization by others, or inability to parent.
- As a family member or support person you may help your young person monitor medications (if they are taking any). Make sure that a medication refill is ordered at least one week prior to running out of medication.

Review the family guidelines and share them with your family (See also: EASA Family Guidelines).

- ✓ The family guidelines were developed to help families in your situation cope and work their way from crisis to recovery. They are simple, important and helpful.
- ✓ Many families hang the guidelines on their refrigerators or put them in a place where they will see them often.

Complete the agency intake process.

Your EASA team will walk you through the intake process. The goal of EASA is to make the best care available as soon as possible regardless of ability to pay or other barriers. We want to make sure you have no surprises as far as billing. You will want to ask your EASA team what services will cost (if anything), and to problem solve if necessary to make sure your young person has health insurance or some other subsidy. EASA has a state subsidy to help with costs, but it will be important for you to know what the costs are and insurance options.

Help your young person access the best health insurance available to them.

EASA state dollars cover outpatient care, but not medicine, crisis, or emergency room and hospitalization services. Oregon Health Plan covers all of these things but private insurance often has limited coverage. Your young person may qualify for Oregon Health Plan if you do not count them as a dependent on your taxes or they may also qualify



based on income. Ask your EASA team members to help your young person apply for Oregon Health Plan to see if they qualify.

Share information with the team to help with the assessment.

Download the Family Input Form (http://www.easacommunity.org/PDF/EASA_family_input_form_Nov_2012.pdf) or ask an EASA team member to give you a copy to fill out. This form guides you through information that will be helpful for the team in understanding your young person's needs and how to engage and support your young person and family.

Help your young person track and get to appointments.

Your EASA team members can assist your young person to problem solve remembering appointments and figuring out transportation to and from appointments. Your EASA team members can also remind you and your young person of appointments via text, email, or phone, depending on preference.

Help your young person follow up on medical testing that the psychiatrist or psychiatric nurse requests.

Your EASA team members can assist with helping your young person get to their appointments for any recommended testing.

Schedule time with the EASA team to meet with them.

You can and are encouraged to meet directly with all team members involved in your young person's care, to share information, ask for support, ask questions and give feedback.

Begin to read about the basics: symptoms, communication, impact on family members, treatment, and recovery. The more you educate yourself the better you will be able to help your young person. A good place to start is EASA's website, www.easacommunity.org. Ask your EASA team to give you written and verbal information about psychosis risk syndrome or psychosis or to recommend books and websites that have information for you to read.

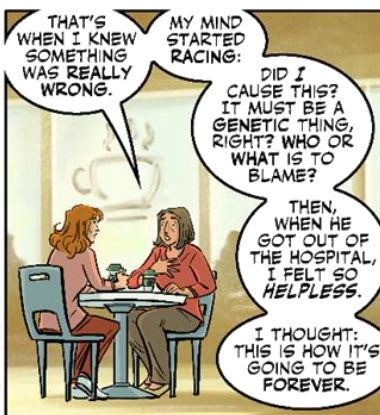
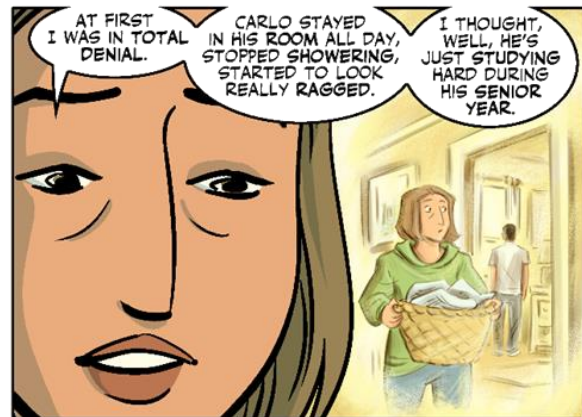
**Your EASA team
is here to help!**



EASA Family Guidelines

1. Believe in your power to affect the outcome: you can!
2. One step at a time.
3. Consider using medication to protect your future, if the doctor recommends it.
4. Reduce stresses and responsibilities for a while.
5. Use the symptoms as indicators.
6. Anticipate life stresses.
7. Keep it calm.
8. Give each other space.
9. Set a few simple limits.
10. Ignore what you can't change.
11. Keep it simple.
12. Carry on business as usual.
13. Solve problems step by step.
14. Keep a balanced life and balanced perspective.
15. Avoid alcohol and non-prescription substances.
16. Explain your circumstances to your closest friends and relatives and ask them for help and to stand by you.
17. Don't move abruptly or far away until stability returns.
18. Attend the multi-family groups.
19. Follow the recovery plan.
20. KEEP HOPE ALIVE!





Dialog by Craigan Usher, MD • Art by Colleen Coover

For more information, visit www.easacommunity.org



The EASA Center for Excellence

The EASA Center for Excellence (EASA C4E) provides training, technical assistance, consultation, and support for program development and quality improvement for EASA programs statewide, as well as for national early psychosis programs. The EASA Center for Excellence is a collaboration between Portland State University and Oregon Health & Science University through the OHSU-PSU School of Public Health. The Oregon Health Authority sponsors all EASA programs and the Center for Excellence with funding and other forms of program support. The EASA Center for Excellence maintains a website that includes information and resources for young people and their family members and supports at www.easacommunity.org.

Members of the Center for Excellence team travel around the state visiting local EASA programs to provide trainings and consultation, as well as to conduct fidelity reviews. In addition, Julie Magers facilitates the Family and Friends Leadership Council (FFLC) and Michelle Owens facilitates the Young Adult Leadership Council (YALC). Your EASA team can connect you or your young person with FFLC or YALC (see section on [Connection to Others](#)).

Our Mission: To improve services for individuals with early psychosis and their families.

Our Vision: We envision a society—from the largest systems of care to individuals' unique support networks—that values the lived experience and perspectives of every person, and is able to mobilize quickly and effectively to meet the needs of young people who are experiencing mental health challenges, particularly those who are having symptoms of psychosis or who are at-risk for psychosis.

Our Values:

- **Diversity:** We celebrate diversity and honor the unique challenges that people face as well as the strengths and creativity they demonstrate in meeting those challenges
- **Experience:** We respect and listen to lived experience, acting upon what we learn
- **Evidence:** We examine, disseminate, and contribute to up-to-date, evidence-based data that informs policy and practice
- **Community:** We are sustained, informed and energized by and members of a community young people, families, friends, peer specialists, and others
- **Leadership:** We are excited to be part of a local, national, and international community that establishes, examines, and disseminates best practices for at-risk youth and those with first-episode and early psychosis
- **Teamwork:** We practice and collaborate utilizing a transdisciplinary approach



Meet the EASA Center for Excellence Team!



Tamara Sale, MA
Center Director

Ms. Sale has been responsible for the overall development and implementation of early psychosis services in Oregon for many years, and also currently consults with mental health professionals nationwide to help launch new programs similar to EASA.



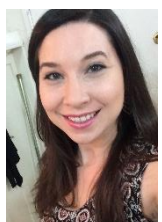
Megan Sage, DSW, LCSW, MSW
Program Development and Equity Director

Megan provides clinical consultation, training, fidelity reviews, and program development for Oregon EASA programs and similar programs in several other states. Megan brings a focus on equity and culturally-informed interventions, with nearly a decade of experience providing services to EASA participants and families as a bilingual mental health consultant.



Katie Hayden-Lewis, PhD LPC
Rural Services Director

Dr. Hayden-Lewis' priority focus is supporting rural and frontier EASA programs with clinical and infrastructure adaptations designed to meet the needs of remote communities. Katie's primary research focus is in youth identity development post-psychosis with pursuits in trauma sensitive and transformative justice clinical practices in CHRp and FEP research and care.



Halley Knowles, MPH, CPH
Program Manager

Halley has been providing administration for EASA Center for Excellence since the program joined Portland State University in 2013. She is the organizational headquarters of many things EASA, including project management, trainings and certification, communications and web development, and liaising EASA C4E with Oregon EASA sites and national partners.





Dr. Craigan Usher, MD

Psychiatric Consultant

Dr. Usher is the associate training director for the OHSU Division of Child and Adolescent Psychiatry and was formerly a psychiatrist for Washington County EASA. Craigan continually pursues the links between the neuroscience of empathy and attachment and child psychiatric practice in his work.



Tania Kneuer, OT/L

Occupational Therapy Consultant

Tania provides support as the Occupational Therapy lead for all Oregon EASA programs, including clinical support with professional and OT-specific program development. She assists various EASA sites with consultation and clinical training. Her passion is the incorporation of the occupational therapy perspective for transdisciplinary comprehensive care.



Michelle Owens

Young Adult Engagement Specialist

Michelle Owens works with the Young Adult Leadership Council to extend opportunities for youth voice and leadership in EASA programs. As a Peer Support Specialist herself, Michelle supports EASA Peer Support Specialists in their roles and the implementation of peer support across EASA sites.



Understanding EASA's Philosophy and Approach

EASA reinforces and builds on each individual and family's unique strengths, beliefs, perspectives, worldviews, and culture. We want to know how you and your young person and other family members and friends make sense of their experiences so that we can work with everyone in a way that best meets their needs, values, and beliefs. At times, young people can have different perspectives on their experiences than their parent(s), other members of their family or their friends. The EASA team works everyone to come to a shared understanding that respects and incorporates all viewpoints.

EASA genuinely believes that each person will do well with the right support and opportunities.

Communication and shared decision making processes are core to what EASA does. (See also **Answers to Common Questions: What is Shared Decision Making?**)

EASA supports you and your young person in a **holistic** way. That means EASA team members work on the goals that matter most to you and your young

person, including medical needs, school and work, living situation, relationships, and other things that are important to you and your young person.

Family members are essential partners with the EASA team. **Your knowledge and perspective cannot be replaced.**

EASA offers multiple disciplines, backgrounds, and perspectives on one team. EASA teams vary in size, but typically have a psychiatrist or psychiatric nurse practitioner, nurses,

counselors, peer support specialists, supported employment & education specialists, and occupational therapists.

There are some EASA teams where not all of those disciplines are present. When that is true, EASA teams build on the knowledge and perspectives of those disciplines to incorporate them into treatment.

EASA values feedback and learning from experience. Your EASA team wants you to let them know what they can do to better support you and others.



EASA tries to make it as easy and comfortable as possible for people to engage. EASA does our best to respond to what everyone needs while helping the young person maintain a sense of control and build skills.

EASA values honesty and transparency, which means that we want people to tell us what they really think and what they are really choosing. Your EASA team will not lie to you or your loved one, and we encourage families to do the same with each other and their EASA team.

EASA practices harm reduction. This means EASA teams know that sometimes young people make choices that can be harmful, and EASA team members can encourage them to make better choices without pushing them out of treatment.



EASA may recommend that a young person receive more intensive care beyond EASA for substance use or to address other issues. If a different type of care or level of care is indicated based on their individual needs, your EASA team will work closely with you and your young person to coordinate services.

EASA does not ignore safety concerns. If someone's situation or behavior puts them or others at significant risk EASA will do whatever we can to keep people safe.

EASA values differences and believe that each of us carries our own truth. EASA understands that families that love each other and that conflict comes up. EASA actively works with families to come together and develop a shared understanding.



EASA is a network.

There are EASA programs throughout Oregon and similar programs throughout the United States and in other parts of the world. If your young person moves, or you live in different communities, EASA will work to connect you with resources close to home.

EASA is a transitional program but in it for the long-term. EASA typically works intensively with you, your young person, family members, and other supports for two years, with a gradual transition into ongoing resources after graduation. EASA's programs and leadership network work together to build long-term community. EASA strives to support our graduates through advocacy and opportunities for long-term involvement.



Questions to Ask my EASA Team:

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SECTION 2: THE EASA SERVICE PERIOD





We've seen a dramatic improvement in our son since he joined EASA.

EASA Parent

"We have needed many different services for our son since he was 3 years old and had to fight for everything for him. With EASA it's completely different— we kind of have the dream team!"

EASA Parent



Multi-Family Group helped with the family piece— earlier on we focused a lot on problem-solving.

EASA Parent



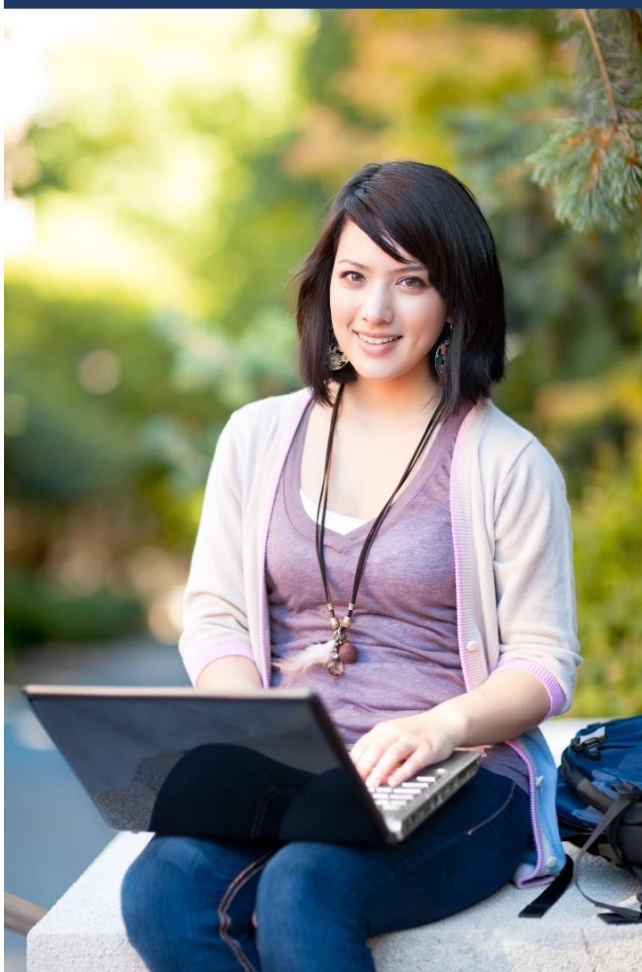
*They have
somebody to help
you with literally
every aspect of your
life.*

EASA Participant



*They take the time
to listen to you.*

EASA Participant



I feel like I'm not alone in my experience.

EASA Participant





Who is on my EASA team?

EASA uses a team approach. Collaboration and teamwork are at the heart of EASA.

EASA teams consist of different team members that may include a therapist, doctor, nurse, occupational therapist, young adult peer support specialist, case manager, supported employment and education specialist, and/or housing specialist. The entire EASA team works with you and your young person to solve problems that will support your young person in achieving their goals. For example, if your young person wants to change their medications or move into an apartment on their own, everyone discusses these topics together to come up with a solution. EASA's philosophy is that everyone has important knowledge and skills, and that the best solutions come when everyone works together as a team. EASA team members use evidence-based approaches to care and provide intensive services and support. All EASA team members work collaboratively together to provide the most effective services for you, your family, and your young person.

Your EASA team may include any of the following people or groups. Smaller programs may combine roles and disciplines.



Counselor, case manager, therapist, clinician, or mental health consultant

Your counselor's job is to help your young person identify and meet their goals. They will get to know your young person's strengths and the strengths of your family and community. The counselor will use a variety of strengths-based approaches and techniques, including cognitive behavioral therapy (CBT), mindfulness, motivational interviewing (MI), and psychoeducation. These approaches may be provided individually or in group settings. The counselor will help your young person achieve their individual and family goals by:

- ✓ Locating resources like housing, benefits, transportation, or support groups
- ✓ Connecting your young person with other services both within EASA and in the community
- ✓ Working with your young person and family members to overcome challenges and build on strengths



Psychiatrist, nurse practitioner, or licensed medical provider

The psychiatrist or nurse practitioner on your EASA team is a licensed medical provider (LMP) who meets with you, your young person, and other supporters (with permission). No EASA participant is required to take medication to be a part of the EASA program. However, even if your young person is not taking medication, you are encouraged to meet with the EASA licensed medical provider (a psychiatrist or nurse practitioner) on a regular



basis to share information and talk about any healthcare needs or questions that you may have.

Your psychiatrist or nurse practitioner's job is to help your young person focus on wellness and recovery. They will explain any medical diagnoses your young person has and provide medical information to you and your young person in order to make informed decisions. A psychiatrist or nurse practitioner can also help your young person decide about medications and manage any medications they choose to take. They will help monitor your young person's overall health and coordinate needs with their primary care doctor. A licensed medical provider will answer questions and provide information to you and your family members and supports (with permission), as well as:

- ✓ Provide educational information about symptoms, medication, and side effects
- ✓ Make recommendations about medications that may be helpful
- ✓ Make a plan with you to meet your young person's healthcare goals
- ✓ Communicate medical information to other healthcare providers



Nurse

EASA nurses work with your young person to address mental, physical, and overall health care needs. The nurse provides in-depth information about health resources and supports your young person in developing and maintaining healthy habits.

EASA nurses:

- ✓ Provide information regarding overall health, such as nutrition and exercise.
- ✓ Help your young person develop habits that lead to better sleep
- ✓ Provide education regarding sexual health
- ✓ Help manage other medical conditions your young person may have
- ✓ Assists with access to medications and pays attention to any side effects
- ✓ Provide more in-depth information about health resources related to your young person's interests and needs (for example, if your young person wants to stop using tobacco or become more physically active the nurse will provide support and education to help your young person achieve that goal)

If your EASA team does not have a registered nurse, the EASA licensed medical provider and other team members will assist your young person with wellness and health habits.



Occupational therapist

Occupational therapists help your young person build the skills and environment they need in order to succeed in work, school, and relationships.

Occupational therapists:



- ✓ Learn about the types of environments where your young person does well through an individualized assessment of how their body responds to different sensations and feelings
- ✓ Teach and help your young person develop a deeper understanding of how to create long term changes with activities that might be causing problems (for example, help with routine, finding activities they enjoy, strategies for mental flexibility when making decisions, developing healthy sleep habits)
- ✓ Come up with solutions that you, your family, support system, teachers, and employers might use to make the environments your young person spends time in be a better fit for their needs
- ✓ Help your young person identify challenges in work, school, and relationships in order to build new strategies, patterns, and skills to manage those challenges

If your EASA team does not have an occupational therapist, other team members will work with your young person to help build these skills.



Skills trainer

Skills trainers help your young person with resources and additional supports, as well as helping them build and use skills that will help them reach their goals.

Skills trainers:

- ✓ Connect your young person to a variety of resources, including housing, benefits, and health insurance
- ✓ Work with your young person to help them learn and build on skills specific to their strengths, needs, and goals

If your EASA team does not have a skills trainer, other team members will work with your young person to help build these skills.



Peer support specialist

A peer support specialist is someone who has gone through similar situations to those that EASA participants have experienced. They use this shared experience to help support your young person and give them feedback from the perspective of someone who has been there. Your counselor is usually the person who matches your young person with a peer support specialist.

Peer support specialists:

- ✓ Draw on their own lived experience to support your young person in feeling less alone and more connected to others
- ✓ Provide hope and encouragement through their stories of lived experience to you, your young person, other family members, and your support system
- ✓ Encourage your young person to advocate for their needs in a way that makes sense for them



- ✓ Support your young person in getting involved in activities they enjoy in the community



School or work specialist

The school or work specialist will help your young person take direct action to achieve school and/or work goals. Some ways that the school or work specialist can support your young person:

- ✓ Help your young person reach high school, trade school, college, job, or career goals
- ✓ Help your young person navigate challenges in school and work that they might face on their way to reaching these goals
- ✓ Support your young person in finding and keeping a job that is right for them, including connecting them to employers who are looking for someone with their skills and talents
- ✓ Help your young person return to school or stay in school
- ✓ Help your young person apply for work and education opportunities after they graduate high school or college



Multi-family groups or single-family sessions

Multi-family groups or single-family sessions are another very important part of EASA services¹⁶. In multi-family groups, EASA team members co-facilitate groups with you, your young person, and other members of your family along with other EASA participants and their families to problem-solve challenges.

Multi-family groups are structured problem-solving groups where each person talks about something that has recently gone well for them and something that has been a challenge. Then the group chooses one person's challenge to brainstorm possible ways to solve in the next two weeks. Ask your EASA team to set up joining sessions for you and your family so that you can join multi-family groups.

If there is not a multi-family group that meets your needs or schedule, your EASA team will still provide joining sessions as well as single-family problem-solving sessions with you and your family in your home or at a location of your choice. Ask your EASA team about options for single family sessions if you and your family members are not able to attend multi-family group sessions.



What Family Members and Friends Can Expect from EASA

- ✓ Partnership. EASA works because everyone comes together in support of your young person.
- ✓ Communication. EASA teams work to include family members and friends from the time your young person is referred. That means your EASA team will want to know who is in your family/support network and make contact with them as soon as possible from the beginning of treatment to offer support, education, and opportunities for involvement.
- ✓ Active effort to engage you and your young person. Your EASA team understands that you are busy and it can be hard to balance all the demands of life. Your EASA team will try to make things as easy and simple as we can by being flexible about when and where we meet and strive to meet your family's individual needs. Sometimes young people are not ready to become actively involved and engaged in EASA right away. We understand that this happens and we will work with you to support you and understand your young person's strengths, motivations, and needs. One of the assessments EASA teams do with young people and their family members early on is a **comprehensive strengths assessment**. Your EASA team will work to gain trust with your young person to help them feel comfortable. Building trust can take time, sometimes up to a year or more, and EASA team members work to be adaptable, flexible, and persistent in engaging young people and their supports.
- ✓ Support. Families need someone to listen, to empathize, to educate, and to problem solve. It is important that you know you are not alone. Reach out to your EASA team when you need to and expect that we will reach out to you. If you have questions or if there is something your EASA team can do to better meet your needs, please let us know. Knowing how to best support you and your young person is very important to EASA.
- ✓ Sharing of information and resources. Your EASA team will share information with you in stages over time based on what you need and what we know. Your EASA team can repeat the information as many times as you need. It can be hard to remember things when experiencing stress, and it can take a while to start making sense of all the information you're being presented with. If you want to learn more about EASA, you can always visit the website www.easacommunity.org to find more information, including a Friends and Families section specifically designed for you. You can expect your EASA team to share information about the following:
 - The assessment and treatment process and how we make decisions
 - What we think is happening with your young person medically and the symptoms they are experiencing
 - Specific information about symptoms and what we know about causes
 - Information about treatment options including involving you in decisions about treatment with permission
 - Information about rights and resources



- The recovery process and how you can help support your young person in their recovery (See also sections on **Tools for Treatment and Recovery** and **Taking Care of Yourself** in the Participant Manual).
- ✓ Involvement in planning
 - Your EASA team will develop a plan with you and your young person that will guide your young person's treatment and their experience in EASA. This plan is based on the goals and needs of your young person and your family. This plan is sometimes also referred to as a **service plan**, and it is required by law for those receiving services. Some teams refer to them as "treatment plans," "recovery plans," or use another term. Ask your EASA team about this plan and how you can be actively involved in helping to add to it or change it over time.
 - From the very beginning, your team will work with you and your young person to create a **crisis plan**. This plan gives step-by-step instructions about what to do if you find yourself in crisis.
 - The team will also work with you to develop a **relapse prevention plan**. This is a plan explaining what you and your young person can do to prevent symptoms from getting worse, and to get help quickly when you need it.
 - During and after the initial assessment, and then at least once every 3 months, we will sit down with your young person and whomever is involved from the family and support network to review the service or treatment plan, progress, and future plans.
- ✓ Gradual transition. The EASA program typically lasts two years. The first six months your EASA team spends time getting to know you, your young person, their strengths and goals, as well as those of your family, and working together to help you get through any major challenges you are dealing with. The rest of your time in EASA builds on the work you do in those first six months. During your time in EASA, you will have opportunities for you, your young person, and other family members to learn and connect with others who share similar experiences, and gain skills that will help you move into the future life you want. Approximately six months before transition out of EASA, the team will work with you to refine and implement a long-term support plan.



Information about Assessment and Diagnosis

Many young people who come to EASA are experiencing changes that may be difficult to get a clear understanding of in the short-term. Your EASA team will work with you, your young person, and possibly other medical providers, such as a primary care provider, to have a thorough medical evaluation completed. The brain goes through significant changes during adolescent and young adult years, and symptoms of psychosis risk syndrome or psychosis can be caused by a variety of conditions and vulnerabilities. Part of the process of working with EASA is to pinpoint the most accurate diagnosis for your young person, which can take time.

There are a range of experiences that are considered “typical” for youth and young adults depending on their culture, beliefs, perspectives, worldview, and environment. There are many different ideas and beliefs about why some people experience what is commonly defined as psychosis risk syndrome or psychosis. People are learning more every day about what is happening in the brain during psychosis risk syndrome or psychosis. However, there is still not “one right answer.” Symptoms of psychosis risk syndrome or psychosis can affect individuals of any race, gender, sex, nationality, religion, educational background, cultural identity, age, socioeconomic status, and ability. Even though these experiences are common in the full range of human diversity, they are also very individual experiences. Your young person’s experiences may share some things in common with other young people in the EASA program. However, everyone has their own individual experiences, strengths, challenges, and places they are coming from that are unique to them.

Your EASA team honors the importance of each individual looking at their experiences through their own values, beliefs, and perspectives and that of their young person, family members, friends, and/or supports. You and/or your young person and other family members, friends, or supports may experience diversity in terms of race, gender identity, sexual identity, ability, religion, culture, occupation, or in other ways. The things that make you diverse are important, valuable, and amazing parts of who you are and can be great strengths. You are encouraged to share your values, beliefs, and perspectives with your EASA team so that they can support you, your young person, and other family members, friends, and supports in ways that work best for you.

It is possible that what happens as far as reasons for developing psychosis risk syndrome or psychosis is different depending on the person. It is also possible that there is more than one thing happening that causes these symptoms. It is also possible that what is happening has not been understood yet. There are, however, some ideas that researchers have figured out.

One idea is that structural changes or differences in the brain leads to someone experiencing the world or themselves differently than they used to. Psychosis risk syndrome and psychosis can affect the brain's ability to process information. These experiences can also affect sensory perception, ability to organize information, and ability to express information.



There are other less "medical" ways some people use to explain or understand these experiences. There is no "right" or "wrong" perspective. It is okay to hold more than one way of understanding at the same time. Your family members and/or friends may have different ways of understanding or different beliefs about your experiences than you do. The important thing is having ways of understanding or explaining that fit for you.

Another perspective on psychosis risk syndrome and psychosis is called "neurodiversity." Neurodiversity means that psychosis risk syndrome, psychosis and other mental differences like them are natural, normal, and necessary part of human diversity, just like eye color or gender. And, like eye color and gender, the way someone thinks and perceives is a part of someone's unique and valuable identity that deserves to be respected. From a neurodiversity perspective, people who think differently have been important to making innovations in the world.

Spirituality can bring meaning to experiences, create a sense of connection, or foster a relationship with a higher power or powers. Spirituality is one way people organize and make meaning of their lives. Some people view challenges as an opportunity to grow spiritually. Interpreting your experiences spiritually may help someone find meaning in events and create a sense of connection and hope from distress, disconnection, and isolation. For some people, following a spiritual path, or being part of a spiritual community, gives them tools to work towards mastery, or to manage, psychosis.

There are many different cultural beliefs about mental health. Not all cultures view psychosis risk syndrome or psychosis as a mental health concern. Some see symptoms of psychosis risk syndrome or psychosis as a step on a spiritual journey, or part of a spiritual process. For places where connections to ancestors or spirit-worlds are part of mainstream culture, these experiences are often viewed as a connection to these ancestral or spirit-worlds. Your own culture may have unique perspectives and supports to offer. If these perspectives are not part of your culture, you may want to learn more about them.

Some people form their own interpretation of their experiences. These personal interpretations can exist on their own or in addition to other perspectives. This is a normal part of figuring out what the experience of psychosis risk syndrome or psychosis means for each individual. Talking with your EASA team and others about different ideas, worldviews, and perspectives will help you, your young person, and your family members and friends come to their own understanding of the experiences.

No one knows exactly what can cause a person to be at risk for psychosis risk syndrome or psychosis. It is thought to be due to a variety of "biopsychosocial" factors. These factors may be different for different people.

"Biopsychosocial" means a combination of a person's biology (bio), their psychology (psycho), and their social environment (social). The idea is that psychosis risk syndrome or psychosis might be caused by any combination of:



- ✓ a person's genetics, brain development, or other physical traits (**biological**);
- ✓ the way a person copes mentally and emotionally with stress and challenges (**psychological**);
- ✓ other things in a person's life such as substance use, how they are treated by others, or stress at school and/or work (**social**).

Research shows that everyone has the potential to have these experiences. Some people who are vulnerable to developing psychosis risk syndrome or psychosis need to manage it on an ongoing basis.

Some risk factors are:

Biological Risk Factors:

- ✓ Having a family member who has experienced psychosis, especially one or both parents
- ✓ Having other brain or neurological differences, including mental health conditions like depression or anxiety
- ✓ Not sleeping or eating well, or being sick

Psychological Risk Factors:

- ✓ Trauma or traumatic experiences
- ✓ Difficulty finding good ways to manage stress
- ✓ Struggling to understand one's place in the world, or answer questions around "why am I here?" and "what should I be doing with my life?"
- ✓ Feeling hopeless or down about the world or oneself

Social Risk Factors:

- ✓ Using substances, including marijuana, or alcohol
- ✓ Being rejected by, or treated badly by, other people, or having stressful relationships
- ✓ School or work stress
- ✓ Not having a good support network, or not having people who communicate well in one's life
- ✓ Big life events like starting a new school, a new job, or a new relationship

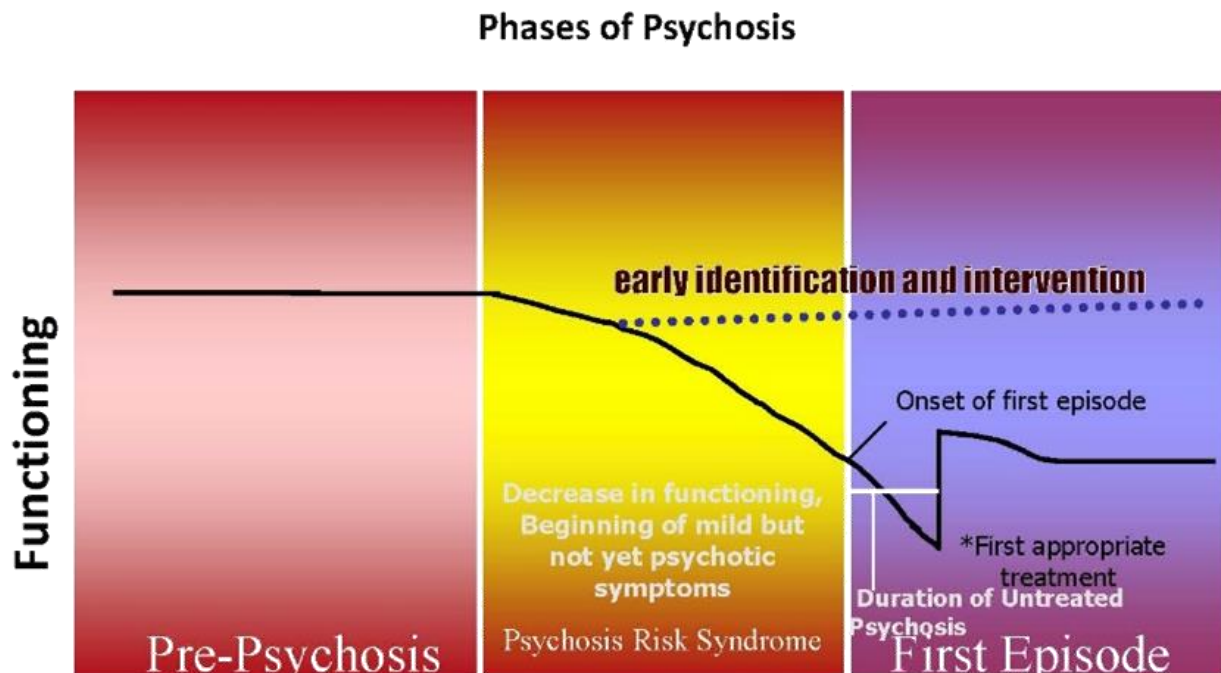
None of these factors alone are the single cause of psychosis risk syndrome or psychosis. Just because these factors are present in a person's life does not mean they will experience psychosis risk syndrome or psychosis. Nor might these factors be the cause of any of the symptoms that your young person may have experienced. However, anyone who has many of these factors in their life is at a higher risk for developing symptoms of psychosis risk syndrome or psychosis. Some of these risk factors--like substance use or big life events--may trigger symptoms of psychosis risk syndrome or psychosis.



While genetics cannot be changed, many possible risk factors can be impacted. These are called protective factors. For example, helping your young person learn ways to deal with stress and helpful ways to communicate, quitting or reducing use of drinking or substances, reducing work or school stress, or strengthening social support networks can help protect against psychosis risk syndrome or psychosis. This is true even after someone has experienced symptoms for the first time.

Psychosis Risk Syndrome vs. First Episode Psychosis: What's the difference?

EASA works with young people who have a diagnosis of psychosis risk syndrome or first episode psychosis. Psychosis risk syndrome is a set of symptoms that contain possible risk factors for developing first episode psychosis. EASA works with young people with psychosis risk syndrome in order to possibly prevent first episode psychosis or, at the very least, some of the challenges that may come with first episode psychosis. Functioning decreases during the psychosis risk phase as mild symptoms begin and evidence suggests intervening at this phase can reduce the intensity of symptoms and/or improve outcomes.



SAMHSA
Substance Abuse and Mental Health
Services Administration



More information on Psychosis Risk Syndrome

EASA uses a very specific, detailed instrument called the Structured Interview for Psychosis Risk Syndrome¹² (SIPS) to determine if your family member or friend has psychosis risk syndrome. It is important to note that even if the SIPS interviewer diagnoses a psychosis risk syndrome it does not mean a young person will develop a first episode of psychosis. It only means that they may be at risk of developing one of those conditions. If a SIPS is completed with your young person and it shows that they are at risk for developing one of these conditions, don't worry—programs like EASA have shown very good outcomes in supporting individuals who have been diagnosed with psychosis risk syndrome.

Psychosis risk syndrome symptoms can range from hardly noticeable to obvious. They can occur over days, months or even years. Unlike first episode psychosis, the young person will retain awareness that their experiences are different than their usual experiences but cause some distress. They are also more likely to seek assistance for these experiences than individuals diagnosed with first episode psychosis.

Here are some common psychosis risk syndrome symptoms:

- ✓ Sensitivity to light, touch and sounds
- ✓ Trouble concentrating, paying attention, and with memory
- ✓ Having a hard time understanding others and being understood when talking
- ✓ Increased suspicion and fear without a known reason
- ✓ Momentarily thinking they see or hear something that is not there
- ✓ Unusual ideas or behavior that is new and different for them
- ✓ Struggles in school, at work or with family/friends
- ✓ Withdrawal from important people in their lives
- ✓ Depression
- ✓ Lack of motivation and/or energy
- ✓ Sleep challenges
- ✓ Change in appetite

It is important to understand that it is usually a combination of these symptoms, rather than just one, that suggest a psychosis risk syndrome. These symptoms can also be explained by other mental health conditions, big life changes, stressors, or may be typical experiences of being a young person.

A SIPS assessment completed by a trained professional will tease out possible explanations for these symptoms. In most situations, symptoms of psychosis risk syndrome start gradually, but are **new and uncharacteristic** of the young persons' experiences, personality and behavior.



Recovery with Psychosis risk Syndrome

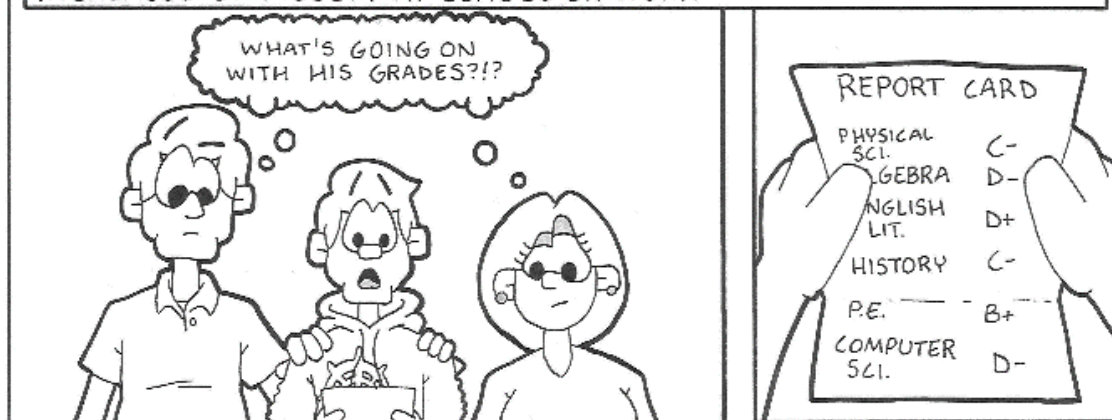
It is important for you, other family members and friends (with participant permission) to know whether or not the young person they are supporting is in EASA due to psychosis risk syndrome. If you are unclear, please ask an EASA team member. Young people with psychosis risk syndrome need to be monitored carefully for any increases and/or improvement in symptoms, both for the purposes of clarifying diagnosis and so that treatment with EASA can be adapted to address their specific needs. Recovery with psychosis risk syndrome varies depending on the individual. Sometimes symptoms of psychosis risk syndrome go away with treatment and support and do not return. For others, symptoms progress into symptoms of psychosis. Receiving treatment and support right away can make a significant difference for a young person experiencing psychosis risk syndrome.

Notes:

[illegible]

PSYCHOSIS RISK SYNDROME SYMPTOMS

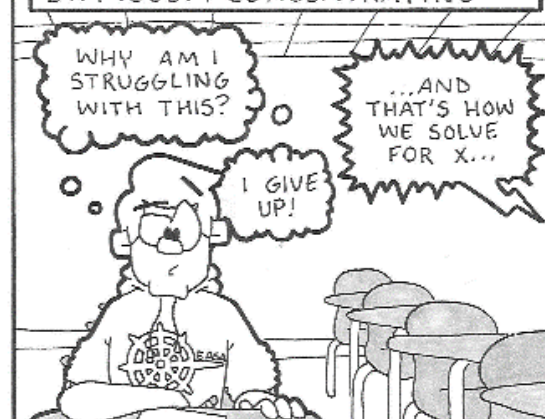
INCREASED DIFFICULTY AT SCHOOL OR WORK



WITHDRAWAL FROM OTHERS



DIFFICULTY CONCENTRATING

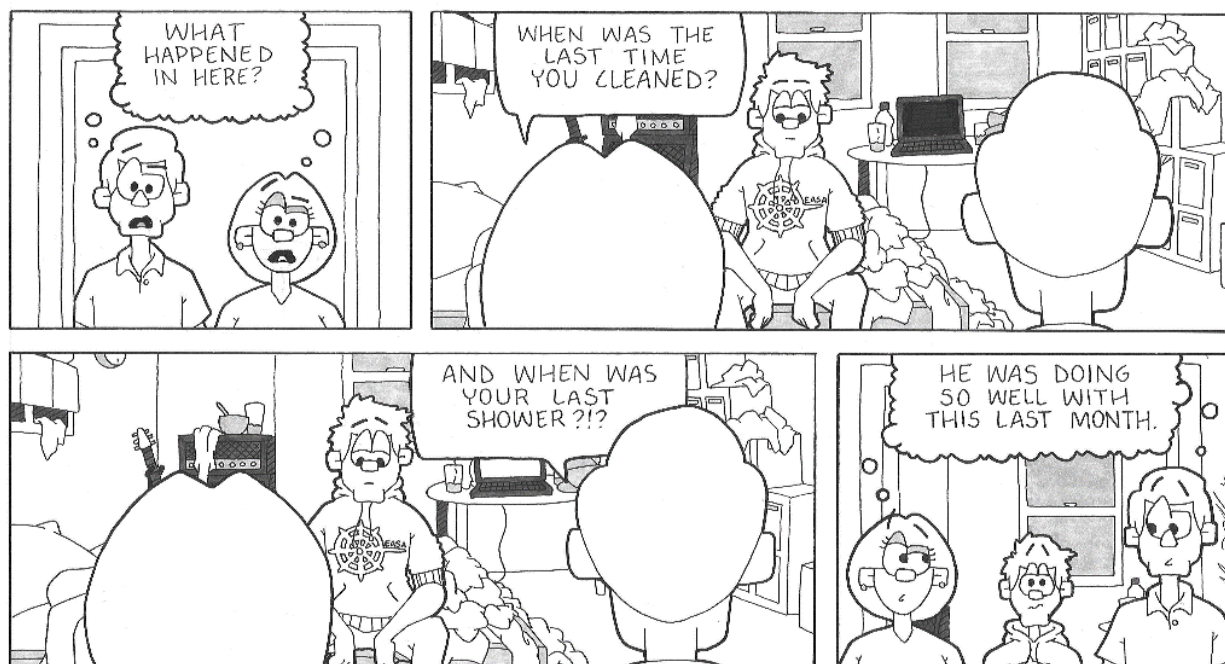


SUSPICIOUS OF OTHERS



THIS IS A CHANGE FROM PREVIOUS BEHAVIORS...





More on First Episode Psychosis or Bipolar Disorder with Psychosis

EASA works with youth and young adults who are at risk for developing symptoms of psychosis (psychosis risk syndrome) or individuals who have recently experienced a first episode of psychosis. Early on, in the psychosis risk syndrome phase, symptoms may be intermittent and the individual often recognizes that something is different.

As symptoms of psychosis progress, individuals lose their ability to distinguish symptoms from reality, and it becomes more difficult to have a conversation. For example, a person who has auditory hallucinations will hear voices which sound to them as loud and real and a person standing right next to them, even though others don't hear it. An individual whose psychosis has progressed may not believe that other people do not hear the same voices and may not be able to integrate new information from others into their thinking.

Psychosis is a condition which affects the brain's ability to process information. Psychosis can affect sensory perception, ability to organize information, and ability to express information. There are many causes. Everyone has the potential to develop psychosis, for example, if they do not sleep for multiple days in a row, if they take certain substances or develop certain medical conditions, or if they experience extremely severe and prolonged stress. Psychosis has a genetic component, which means that individuals whose family members have experienced psychosis will be at greater risk for developing it themselves. Some people with a particularly great vulnerability to developing psychosis have to manage it as an ongoing condition. Psychosis may also result from, or accompany, a mood disorder such as major depression or bipolar disorder (in which there are dramatic swings in energy level, sleep patterns, mood, and behavior).

Your EASA team will use a variety of assessments to identify the most accurate diagnosis for first episode psychosis. EASA programs, like other treatment providers, use the American Psychiatric Association's DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th edition¹³) to categorize diagnoses of first episode psychosis. Treatment for psychotic disorders includes therapy, medication, and other evidence-based treatments that your EASA team may specialize in.

Each participant enrolled in an EASA program will be given a diagnosis as part of their treatment with EASA. This diagnosis may change over time, and guides treatment and the information and education about what they are experiencing. EASA teams encourage participants and family members and friends to ask the EASA team questions about diagnosis and treatment. EASA teams understand that individuals have different views, perspectives, and beliefs about what they are experiencing, and that other people in their family and support network may hold different views and beliefs as well. EASA teams honor how participants and their family members and friends make sense of their experiences and know that this may change over time.

Some examples of possible primary diagnoses that your young person may receive before they enter EASA services, during, or after their time in EASA are:



Brief psychotic disorder

Brief Psychotic Disorder is diagnosed when symptoms of psychosis last for less than a month, at which point most people recover fully. It usually only happens one time and is often related to a stressful event.

Schizophrenia

This condition is diagnosed when individuals experience changes in behavior and other symptoms, which can include hallucinations (seeing, hearing, tasting, feeling, or smelling things that others do not), delusions (holding false beliefs that do not go away), showing a loss of interest in activities, confused thinking, and/or disorganized speech. These symptoms must last longer than 6 months and affect their functioning at work and/or school, as well as affecting their relationships with others to meet criteria for schizophrenia.

Schizophreniform disorder

A diagnosis of this condition includes symptoms of schizophrenia lasting between 1 and 6 months.

Bipolar disorder with psychotic features

This condition is diagnosed when individuals have extreme changes in mood along with symptoms of psychosis, such as hallucinations or delusions.

Schizoaffective disorder

This condition is diagnosed when individuals have symptoms of both a mood disorder, such as bipolar disorder or depression, and symptoms of schizophrenia.

Delusional disorder

This condition is diagnosed when an individual has delusion(s), or false beliefs that do not go away, lasting for at least one month. These beliefs could be true but are not (for example, someone believing that they are being followed or that their food is being poisoned).

Substance-induced psychotic disorder

This condition is diagnosed when the use of substances or withdrawal from substances (such as methamphetamines, cocaine, or hallucinogens) causes hallucinations, delusions, or disorganized speech.

Other Specified Schizophrenia Spectrum and Other Psychotic Disorder or Unspecified Schizophrenia Spectrum and Other Psychotic Disorder

This condition is diagnosed when an individual experiences hallucinations, delusions, or other symptoms of psychosis due to an unknown cause, indicating more assessment needs to be gathered to be able to provide a clear diagnosis. A clinician can list Psychosis risk Syndrome in this category but it is not a formal DSM-5 diagnosis.

All of the above listed conditions are treated with therapy and sometimes medication, depending on the specific needs of the individual.



Other Conditions

Sometimes young people experience other differences in thinking or feeling in addition to symptoms of psychosis risk syndrome or symptoms of psychosis, for example depression or anxiety. These conditions also occur among people who are not experiencing psychosis risk syndrome or symptoms of psychosis. Sometimes these conditions, called "co-occurring conditions", can add to the stress of psychosis risk syndrome or psychosis.

Here are descriptions of some common co-occurring conditions:

Depression

Depression is more than just feeling sad or having a difficult day, which many people can experience. People faced with depression have five or more of the following experiences, without a break, for two or more weeks:

- ✓ feeling down or sad, or having the blues
- ✓ not being interested in things which used to be fun or interesting
- ✓ weight gain or loss
- ✓ making a lot of agitated motions like pacing or hand-wringing
- ✓ moving or speaking more slowly than usual
- ✓ feeling tired for no reason
- ✓ feeling guilty for no reason
- ✓ thinking a lot about death
- ✓ having trouble concentrating

Depression is usually treated with therapy and/or medication.

Anxiety

People facing anxiety experience a huge amount of worry about everyday things. The worry is so great that it makes it hard for them to live their lives. Some ways anxiety can show up are:

- ✓ Phobia, like a fear of snakes so strong it keeps a person from leaving the house, or a social phobia of interacting with people
- ✓ Obsession, which is a thought, feeling, or sensation that keeps coming up even when it doesn't make sense to have come up. For example, a disturbing image that pops into someone's head hundreds of times a day
- ✓ Compulsion, which is a need to do something over and over even if it does not make sense. For example, checking if the door is locked over and over even though it's just been checked.

Anxiety is usually treated with medication and/or therapy. The therapy is often focused on gradual exposure to the thing or something similar to what is causing the anxiety, or on preventing unwanted compulsions.



Mania

People experiencing mania experience an unusually high, out of control, or irritable mood and increased activity and energy. The latter is required for mania to be diagnosed. It is not just a high mood or extreme irritability. Other experiences related to mania may include:

- ✓ a blown-up out of proportion sense of self-importance
- ✓ sleeplessness
- ✓ racing thoughts (thoughts that come in rapid succession that cannot be slowed or stopped)
- ✓ rapid speech
- ✓ jumping quickly from one topic to another
- ✓ doing things that seem fun or like a good idea but are really risky or likely to have bad consequences, for example spending a lot of money when you don't have money to spend

If increased activity and energy are present with several of the other experiences, your young person may be diagnosed with bipolar disorder. Bipolar disorder is usually treated with therapy and/or medication.

Sleep Difficulties

Sleep is as much of a need for our minds and bodies as food and air. Young adults need 9 to 11 hours of sound sleep a night. Not sleeping, or not sleeping well, can cause mental and physical health problems. Not getting enough good sleep can also make other things a person is struggling with, like psychosis risk syndrome or psychosis, much harder. Some common sleep problems are:

- ✓ insomnia - not being able to fall asleep
- ✓ narcolepsy – feeling very sleepy during waking times
- ✓ restless leg syndrome - trouble falling asleep because of a "creeping" feeling in the legs
- ✓ sleep apnea - difficulty breathing while asleep (snoring)

Different sleep problems will have different treatments or solutions.

Substance Use Disorders

Substance use disorders occur when substance use becomes harmful and gets in the way of someone's goals. "Substances" can mean illegal drugs, prescription drugs, marijuana, tobacco, and alcohol. For some people, substance use can lead to addiction, which affects the way people think, feel, and behave, and can make it harder to deal with other things they struggle with. Symptoms of addiction could be:

- ✓ a strong desire to use the substance
- ✓ a hard or impossible time controlling the use of the substance
- ✓ continuing to use the substance even though it's having bad consequences



- ✓ making the substance use more important than other things in life
- ✓ experiencing increased tolerance (needing to take more to feel the effects of the substance)
- ✓ experiencing physical or psychological withdrawal symptoms when not using the substance

There are many ways to recover from substance use, including therapy and support programs.

Notes:

[illegible]

Recovery in First Episode Psychosis or Bipolar with Psychosis

Recovery from an episode of psychosis is often gradual, and is unique to each individual. Recovery is not a linear, step-by-step process and varies depending on each individual. However, there are some typical experiences in early and later recovery.

Early recovery, which can take up to 9 months after experiencing a first episode of psychosis, typically involves:

- ✓ Individual is learning to cope and figuring things out; may want to be alone more often
- ✓ Individual recognizes limitations; group and social activities may be hard to sustain
- ✓ Individual focuses on communicating with others and checking out others' reactions
- ✓ Individual is often receptive to relapse prevention planning

Later recovery typically involves:

- ✓ Individual demonstrates increase in confidence
- ✓ Social anxiety can continue to be an issue for some individuals
- ✓ Daily structure and future orientation with focus on goals are important
- ✓ Individuals often want to give back to others what they have learned from their own experience

It is very important for young people and their family members to communicate with their EASA team about any changes they see or experience with regard to symptoms with either psychosis risk syndrome or first episode psychosis. This information is helpful in making sure that the EASA team is providing the best services to address symptoms and challenges and help your young person reach their goals.

If a young person begins to experience symptoms of psychosis after a period of time in which they had not experienced symptoms, or if their symptoms become worse, the EASA team will work with you and your young person to address the symptoms so that they can continue working towards their goals without interruption. An increase in symptoms of psychosis does not necessarily mean that your young person will need to go to the hospital, have to start medication, or have to change medications if they are already taking medications. The sooner that you and your young person let an EASA team member know about a change in symptoms the better they can make adjustments in treatment to prevent symptoms from getting worse. The **relapse prevention plan** is an important part of the process of paying attention to an increase or worsening of symptoms (**See: What Family Members and Friends Can Expect from EASA**).

Psychosis: A Wellness Approach, by Mary Moller is a highly useful and comprehensive text. It can be ordered at <http://www.psychiatricwellness.com>.



What EASA Provides During the Two Year Service Period

It can take time, but your EASA team will work with your young person to get to the most accurate diagnosis in order to be able to provide the most appropriate, evidence-based treatment. Your young person's treatment with the EASA team will include a variety of therapeutic interventions that fit best with the needs and strengths of your young person, including:

- ✓ Strengths-based assessment and treatment: Focusing on your young person's positive assets to promote wellness and recovery
- ✓ Cognitive behavioral therapy (CBT): Helping your young person understand how their thoughts and feelings influence their behaviors. CBT can assist your young person in coping with stress, addressing grief, and learning new ways to deal with typical life challenges
- ✓ Motivational interviewing (MI): Helping your young person identify their goals, what may be getting in the way, and help motivate them to reach their goals
- ✓ Harm reduction techniques: Helping your young person reduce high-risk behaviors, such as substance use, that may negatively impact their recovery
- ✓ Individual Resiliency Training (IRT): Helping your young person reach their goals through a focus on strengths and learning new skills
- ✓ Mindfulness strategies: Helping your young person focus on awareness of their thoughts, feelings, physical sensations, and their environment to ground themselves
- ✓ Medications and/or supplements
 - Some examples of medications that may be prescribed for young people with a diagnosis of psychosis include: Abilify, Zyprexa, Risperdal, Seroquel, Latuda, Invega, Rexulti, Clozaril, Trilafon, Haldol. Ask your EASA licensed medical provider to give you information about these medications and their possible side effects.
- ✓ Your EASA team members may specialize in other evidence-based treatments.



Treatment with EASA will be specifically tailored based on your young person's diagnosis (psychosis risk syndrome or first episode psychosis) and their strengths and needs.

If your young person enters EASA services with a diagnosis of psychosis risk syndrome and they develop a first episode of psychosis while in the EASA program, EASA services may be extended beyond the two-year period. Ask your EASA team about how this will work for your young person if they have been diagnosed with psychosis risk syndrome.



Overview of EASA Services and Supports

EASA offers various services and supports to young people and their families over a two-year period. Involvement of family members and friends in services is key to helping your young person recover and achieve their goals. EASA uses a transdisciplinary team approach, which means that all of the team members work together with you and your young person to focus on recovery and accomplishing individual and family goals. EASA team members from different disciplines may come meet with your young person together in the community, or attend appointments with the EASA psychiatrist or nurse practitioner with you and your young person. All EASA team members on your team meet every week to coordinate services for every individual in the EASA program with a focus on the young person's strengths, successes, and goals. Every three months you, your young person, and your EASA team will meet to discuss goals and progress in treatment.

Services offered by EASA teams are provided by professionals trained in psychosis risk syndrome and first episode psychosis intervention. Ask your EASA team members about the following EASA services:

- Outreach and engagement
- Individualized assessment, diagnosis, and treatment planning
- Strengths assessment
- Individual and group counseling
- Single and multi-family groups
- Education and support for individuals/families/primary support systems
- Crisis planning and relapse prevention planning
- Information about rights and benefits
- Assistance with independent living skills for daily living and working
- Information about resources and assistance with connecting to those resources
- Support in school and work settings through Supported Employment and Education services
- Opportunities for mentoring and meeting others with similar experiences
- Medication support and education
- Nursing/Physical health services that focus on wellness

In addition to specialized services that are specific to the needs and goals of your young person and your family, EASA provides many opportunities for family members and friends of participants to connect with others. Your EASA program will offer **educational workshops, multi-family groups**, and may offer other groups for youth and young adults, as well as other groups for family members and friends. There are also opportunities to connect with EASA participants, family members, and friends after graduation from the program (**See also: Connection to Other Young People, Family Members, and Friends Involved in EASA**).



Educational Workshops

Soon after your young person joins the EASA program, your EASA team will invite you to an educational workshop. In this educational workshop you will learn about psychosis risk syndrome, psychosis, treatment (including medications), recovery, as well as be given information about typical adolescent and young adult development and how this differs from symptoms of psychosis risk syndrome or psychosis. You will also learn about coping and communication skills, talk about the EASA Family Guidelines, and talk about common reactions that family members have when their young person experiences symptoms of psychosis risk syndrome or psychosis. You will meet all of the EASA team members who will provide specific information about the services EASA provides, including Multi-Family Groups or single-family sessions (**See Multi-Family Groups or Single-Family Sessions**).

The educational workshop is a relaxed environment where you can ask questions, meet other people in the program, and learn how to best support your young person in their recovery. Each EASA program typically offers educational workshops several times a year, however, some smaller EASA programs will offer the information usually provided in an educational workshop to you and your family members and friends on an individual basis. Your EASA program may provide the information to you in a different format if that is a better fit for your needs. Ask your EASA team about educational workshops.

Your next scheduled educational workshop is:



Your EASA team contact for the workshop is:



Multi-Family Groups or Single-Family Sessions

Once you attend an educational workshop (or receive the information from the workshop on an individual basis) you will begin attending Multi-Family Groups (MFGs) or single-family sessions, which are ongoing problem-solving groups based on best practices in supporting the recovery of young people who have experienced symptoms of psychosis risk syndrome or psychosis¹⁶. Multi-family groups or single-family sessions are a very important part of EASA services and a great way to learn new skills. In multi-family groups you will have the opportunity to connect with other people involved with EASA. Your EASA team members will orient you to the multi-family group or single-family session process and answer any questions you may have. Ask your EASA team members about options for single-family sessions if you cannot attend multi-family groups.

Your next scheduled Multi-Family Group (MFG) or Single-Family Session is:



Your EASA team MFG/Single-family Session contact(s) is / (are):



Answers to Common Questions for Family Members and Friends

What is the best way for me to communicate with my EASA team?

You are an important partner in your young person's care. Your observations about your young person's strengths, the strengths of your family, changes you may observe in your young person, as well as the medical and developmental history of your young person prior to EASA are all important. EASA will work with you to help you understand what may have changed, what may be helpful in supporting your young person, and to make a plan together to move forward.

Assuming your young person gives permission, you may meet separately with EASA team members or join your young person for some or all appointments. Feel free to request these meetings or reach out to any EASA team member to communicate information and get support and/or resources.

When might the team not be able to talk to me or give me information about my young person? (See also: What Family Members and Friends Can Expect from EASA; Confidentiality, Releases of Information, Informed Consent, HIPAA, and Patient Rights)

Under Oregon Law communication with family members regarding individuals over the age of 18. requires a written release of information, sometimes called an ROI, which gives permission for EASA to talk with you regarding your young person's treatment with EASA. There are a few exceptions to this law, which your EASA team can explain. Sometimes the individual does not want to sign a release or is only willing to sign a release to allow communication about a very limited range of information. Even without a signed release, the family can still provide information to the clinical team and receive information from the team which is not specific to your family member, such as how the program works and education about psychosis risk syndrome or psychosis, and ways that families can help. EASA team members can also communicate with you if there is an emergency which might result in a life-threatening situation.

It is important for the EASA team to build trust with your young person in order to engage them in treatment. Sometimes that means that the young person does not want to share all information with their family. When this occurs the EASA team will honor that choice, as it essential to build a trusting relationship. The EASA team will work with the young person to encourage family inclusion and communication when helpful in reaching treatment goals.



What if my young person is accepted into EASA and they decide that they do not want services?

It is sometimes difficult for young people to recognize or accept the need for mental health or other medical treatment. If the person is at risk of harm to self or others, sometimes involuntary treatment is required. However, if there is no imminent risk of harm to self or others, the best approach is for the EASA team to build trust and support the person to make choices related to their own care. This way, they are more likely to understand why they are participating in care and continue choosing treatment in the future. To facilitate this process, the EASA team will engage the young person, along with parents, guardians, and/or other family members where appropriate, in shared decision making.

What is a strengths assessment?

A **strengths assessment** is a way for EASA team members to learn about a young person and their family members, and find out what they do well and what resources and supports they have. Sometimes EASA team members can also use a values card sort activity to discover talents and abilities of young people and their supports. Strengths assessments should be completed with you, your young person, and EASA team members together towards the beginning of your young person's time in EASA. The strengths assessment is a document that will be revisited and revised throughout a young person's time in EASA. See **Appendix A** for a copy of the strengths assessment and ask your EASA team about your young person's strengths assessment.

What is a risk assessment?

A **risk assessment** is a way for EASA team members to learn about potential risks that would cause harm to a young person, their family members or supports, and ways to minimize those risks and keep everyone safe and healthy (See also **Appendix C** for a copy of the comprehensive risk assessment). Risk assessments should be completed with you, your young person, and EASA team members towards the beginning of your young person's time in EASA. The risk assessment is a document that will be revisited and revised throughout a young person's time in EASA. Ask your EASA team about your young person's risk assessment.

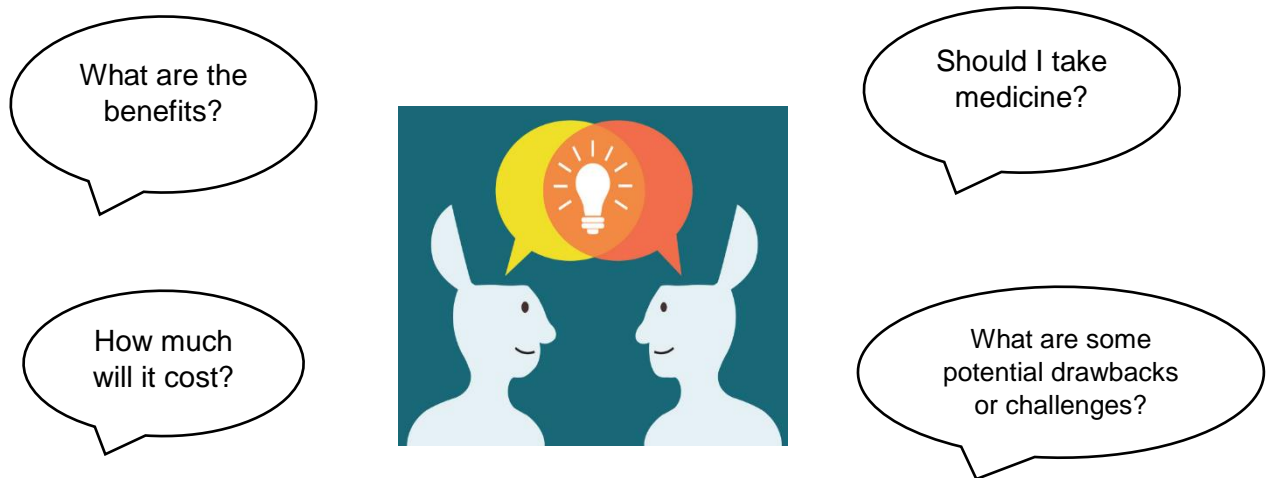
What is EASA's philosophy about how decisions are made?

EASA believes that decisions about treatment, as well as other decisions that come up during treatment, should be made together with young people, their family members (with permission), and EASA team members. This means that a young person and their family members receive information and options on different topics from EASA team members, they have the chance to explore these options, they communicate their concerns and preferences, and then everyone makes a plan together based on that information.

This is an open, transparent process that involves young people and their family members understanding the benefits and risks of different options and making a decision together. EASA teams use this process to help guide decision making throughout a person's time in EASA. This process is used to make informed decisions about medicine and treatment,



as well as to facilitate decision making in other areas that are typical for youth and young adults. These include decisions about whether or not to disclose a medical condition at work, whether to live alone or with roommates, how to remain engaged in school or work after an increase in symptoms, etc. This type of decision making is called Shared Decision Making, or SDM¹⁵.



What is a relapse prevention plan?

Relapse prevention planning is a way to prevent psychosis risk syndrome or psychosis from getting in the way of a young person's goals. It involves identifying the triggers that can cause a relapse in symptoms, identifying the early warning signs that a relapse might happen, and writing a plan for what to do if a relapse happens. These three things—triggers, warning signs, and a plan—together make up a **relapse prevention plan**.

Having a relapse plan does not mean there is a problem that needs fixing, or that anything bad has happened. It is:

1. a tool to help your young person achieve their dreams and goals;
2. a set of things your young person can do on a regular basis to prevent a relapse;
3. a tool that your young person can use to help communicate with others about what they need, and how others can help.

You, your young person, and your EASA team will work together to create a relapse prevention plan to identify the triggers that can cause a relapse, the early warning signs that are unique to your young person, and what to do if a relapse happens. This plan should be revisited throughout your time in EASA and updated as needed. It is a good idea to test out your relapse prevention plan to make sure that it has everything needed included in it. See **Appendix D** for a copy of a relapse prevention plan.



What if my young person does not want to engage in EASA services?

If your young person does not want to be part of EASA, the EASA team can continue to problem solve with you and provide you with resources. Sometimes young people are not quite ready to engage in services when they are first referred but do decide to engage over time or at a different time.

What does “harm reduction” mean?

It is common for youth and young adults to make decisions their parents or guardians do not support, such as using alcohol or marijuana or engaging in risky sexual behavior. Some risk-taking behaviors are a typical part of the developmental process, particularly substance use. Parents and guardians can set their own rules about behavior in their household. In the treatment process, however, it is important for the young person to be able to freely disclose behavior they might not be telling their parents about in order to be able to recognize the impacts of those decisions. EASA teams use a “harm reduction” approach in treatment. This means that we do not require young people to stop behaviors such as substance use in order to participate in the program. However, EASA teams actively work with young people to see how substance use or other behaviors may be interfering with their goals and to encourage them to reduce those behaviors to prevent serious harmful consequences.



How do we learn about other resources?

EASA maintains a website, www.easacommunity.org, which has a wide range of written educational materials, videos, and resources for families. Please let your EASA team know if you need any of these materials or resources in a different format or a language other than English for yourself or other family members.

Notes:

This image shows a full page of blank, lined paper. It features approximately 20 evenly spaced horizontal blue lines across its entire width. The lines are thin and consistent in color, set against a plain white background. There are no margins, text, or other markings present on the page.

Confidentiality, Releases of Information, Informed Consent, HIPAA, and Rights

Confidentiality

Confidentiality and family involvement in a young person's health care can be a confusing topic for young people, family members, and sometimes for medical providers themselves. Many health care practitioners providing care to young people find themselves in a challenging position between honoring the young person's request to keep information private from their parents and honoring the parent's desire to be informed about their young person's care. As a parent or family member, it is important to know what the law says and how to advocate for legal boundaries to be followed. It is also important to know your young person's legal rights, to consider their desire to maintain confidentiality about their own health matters, and to be helpful in your child or young adult's developmental process of becoming self-reliant, self-determined, and responsible for their own health care decisions as they enter adulthood.

Informed Consent

Confidentiality can be confused with informed consent, or consent to care. Informed consent is an agreement by a young person or their legal guardian that is signed when they enter services. The informed consent for treatment states that they:

- ✓ Understand the treatment they will receive,
- ✓ Authorize and allow the treatment, and
- ✓ Understand how private information will be shared

Informed consent for services should include:

- ✓ A description of the treatment being provided to the individual,
- ✓ A description of other treatments,
- ✓ A description of risks and benefits of each treatment.

Releases of information (ROIs)

Communication from your EASA team to you about information your young person has shared or their specific treatment requires your young person age 18 or older to sign a Release of Information (ROI) in most cases. If there is a crisis situation which might be life threatening your EASA team and/or other medical providers may be able to communicate without a signed release, but that is an exception. While EASA encourages family involvement, your young person may not want to sign a release of information that allows your EASA team to talk with all family members. Your EASA team will spend time with the young person talking through their concerns and making sure that they feel comfortable about what is being communicated.

Except in crisis situations, a signed release of Information form is necessary to discuss health information with anyone other than the young person or their legal guardian, for



example, if an EASA team member wants to speak with a school counselor or your young person's primary care physician. A signed Release of Information also allows transfer of your young person's medical information to another medical or mental health provider. A young person age 14 or older can sign an ROI in the state of Oregon. For young people under the age of 14, in most cases, the parent or guardian will consent to medical care and releases of information. At age 14, a young person can access and consent to health care without a parent's permission. However, if the young person is a minor, the parent or guardian must be included in the young person's care before treatment ends.

Depending on their age, minors can request certain levels of confidentiality and consent to some health care matters. Please know that health care professionals may be able, or even required, to disclose certain health information about minor patients to state agencies (such as communicable diseases or suspected abuse or neglect).

If your young person does not want to sign a full release of information, they may agree to sign a limited release that pertains to specific information (for example, appointment dates and times, treatment goals, specific information about their medication, etc.). It can be very helpful to spend some time talking with your young person and EASA team members about releases of information and helping your young person decide what type of information can be shared with whom and for how long.

If your young person does not agree to have any information released to you as a family member, the following things can still happen:

- ✓ You can communicate any information you think is important to EASA team members.
- ✓ You can participate in EASA educational workshops and receive educational information from EASA without specifically talking about the details of your young person's situation.
- ✓ You can problem solve with EASA team members without the EASA team member sharing information covered by confidentiality laws.
- ✓ Two-way communication without a release is possible if anyone's safety is threatened.
- ✓ At the point when your young person is willing to sign a release of information, freer communication will be possible. EASA teams are persistent in encouraging open communication, except in cases where there are active abuse or safety concerns.
- ✓ For more information, ask an EASA team member, search "Minor Rights: Access and Consent to Health Care" on the internet, or visit this website:
www.oregon.gov/oha/ph/HealthyPeopleFamilies/Youth/Documents/minor-rights.pdf



Understanding HIPAA

HIPAA stands for the Health Insurance Portability and Accountability Act. This federal regulation created national standards to protect an individual's identifiable information in health records. HIPAA also allows an individual to have greater access to their own records. HIPAA can be confusing and may be misused. Understanding information regarding HIPAA will help you with important paperwork and decision-making.

What kind of information is included in HIPAA?

Protected health information (PHI) is any information that could identify a person, such as name, address, birthday, social security number, and phone number. It also includes any information about health, diagnosis and/or treatment. A person can authorize a provider to discuss health care needs without giving the details of what has been discussed in a treatment or therapy session.

Confidentiality for substance abuse treatment programs (42CFR Part II) is a federal regulation, like HIPAA. It only applies if you are a current or past patient of a substance abuse treatment program that receives federal funds. The program and its staff cannot disclose that an individual is or has been a patient, nor whether the person has any current or past problems with substance use or abuse.

Coordination with other service providers (See also Confidentiality, Releases of Information, Informed Consent, HIPAA, and Individual's Rights; and Minor Rights: Access and Consent to Health Care)

With permission, EASA teams also collaborate with other providers involved in the care of your young person. This can be hospital staff, primary care physicians, school counselors, family advocates, etc. EASA teams will not release any information about you or your young person to anyone else without permission, except in cases of crisis when information pertinent to their health and safety may be shared in order to keep them safe.

If your young person needs to go to the hospital or a residential treatment center for more intensive care while they are being screened for EASA services or during their ongoing treatment with EASA, your EASA team will continue to be involved in your young person's care with their permission. If your young person is hospitalized in another part of Oregon (for example, if there are no available hospital beds in Portland area hospitals, your young person may be transferred to a hospital in Bend, or vice versa), your EASA team will reach out to the local EASA team where your young person is hospitalized to provide support and information (with permission). You are encouraged to continue to work with your EASA team while your young person is in the hospital and to participate in planning with your EASA team and hospital staff for when your young person leaves hospital care.



Questions and Answers for Parents and Guardians about Confidentiality, Consent to Care, and Rights

What can I tell a provider if my young person over the age of 18 has not signed a release of information?

HIPAA and all other confidentiality rules do NOT control what you say about your young person to a provider. It only controls what the provider says to you. Tell the provider what you know about your young person's behavior, things that are happening at school or with friends and family, and what concerns you about past or future events or behavior. They can receive this information without compromising the confidentiality rights of your young person.

What can a provider tell me if my young person over the age of 18 has not signed a release of information?

Substance use and domestic violence programs cannot tell you if your young person is participating in their program. However, providers can talk to you when it is helpful for your young person's treatment. The provider can guide you in how to talk with your young person about developing a plan of care, a safety plan or a relapse prevention plan. They can also help you talk to your young person about the benefits of signing a release of information that meets the privacy needs of your young person and your own need to know when and how to help. Providers must involve you when there is a threat of suicide or homicide, or urgent medical treatment is needed.

What can I say to my young person about signing a release of information?

It will be helpful to talk to your young person about what information you want to know and what you will do with that information. One way to guide that discussion is to focus on how you and your young person will work together to stay safe and what you may need to do in case of a crisis. You do not need to know what happens in therapy, only what you can do to help with your young person's progress.

What is the goal of signing a release of information?

The goal for the parents and the young person is to talk about sharing responsibility for safety and planning for wellness, harm reduction, and relapse prevention. This is an opportunity to share concerns, reassurances, and plan responsibly together.

What can I do if I think a provider has violated HIPAA rights or is unwilling to honor a request for information?

Contact the individuals involved with reviewing HIPAA violations and/or information requests for the agency where the provider works. Your EASA team members can always help connect you with resources and information if they do not have the answer themselves. If there is a concern about an EASA team member violating HIPAA rights or not honoring a request for information talk with the EASA supervisor or the designated HIPAA staff member for the agency.



EASA's Culture of Feedback

EASA welcomes any informal or formal feedback about services. You are encouraged to ask questions, express concerns, and give ideas and feedback about the services you are receiving throughout your time with EASA, as well as after your young person graduates from EASA. You can give feedback to your EASA program by talking directly to an EASA team member or supervisor, or through participation in focus groups and/ or surveys. EASA team members may also use structured feedback tools throughout treatment to gather information about how treatment is going and what can be improved.

EASA participants, family members, and graduates of EASA programs are encouraged to participate in EASA-specific hiring committees and agency decision-making committees and boards. You are also encouraged to give feedback on written materials, groups, and physical spaces where activities take place. Your voice is incredibly valuable and hearing about your experiences will help us continue to improve our services.

Complaint/Grievance Process

If you are not happy with any aspect of the services you are receiving from your EASA team or any other provider, it is important to talk directly to the people involved, whether that be your counselor, doctor, or anyone else on the team. You can also call a supervisor or an EASA Program Coordinator. Try to be specific about what you need or want to see happen. You always have the right to change case manager or doctor, although there may be limitations of availability within agencies. It can be hard to know how to communicate your concerns or dissatisfactions. It may be helpful to say something like, "I have a concern that I'd like to talk about with you about my young person's care and would like for us to find a time when we can do some problem-solving." This frames an invitation, rather than a confrontation. It also gives us an opportunity to practice similar communication strategies that help in other areas of our lives.

Each agency has a published complaint/grievance process to help resolve problems as they arise. For Oregon Health Plan and other state-funded services, you have the right to appeal a grievance to the state level. It is understandable that you may have worries about voicing concerns. In mental health, we know that it is not uncommon to fear that somehow a complaint will be met with a negative impact on one's care. At EASA, we are aware of this and we also know that almost everything that has been achieved in the mental health system has happened because of advocacy by people who were affected. It is important for decision makers at all levels to hear the stories of the people the "system" is supposed to serve; otherwise, it cannot possibly be responsive or helpful.



Impact of Psychosis Risk Syndrome or First Episode Psychosis on Family Members and Friends

Grief. Having a young person identified as having psychosis risk syndrome or first episode psychosis can have a tremendous impact on all family members and friends. These conditions can be accompanied by a grief process that affects everyone. The stages of the grief process include shock/denial, learning to cope, and acceptance. Individuals at different stages of grief need different things.

Family conflict. Family members are often at different places in the grief process, which may cause conflict. As families continue to deal with psychosis risk syndrome or first episode psychosis, they may go through the grief process many times. This is typical. However, it is also important to pay attention to how family members are affected by the stress and grief, and not to hesitate to get additional counseling. Psychosis risk syndrome or first episode psychosis can cause challenges within marriages and family relationships, as individuals may reach different conclusions about how to handle the situation. Patience and communication skills become critically important.

Developmental impact. Psychosis risk syndrome and symptoms of first episode psychosis can have a direct effect on development. One of the goals of early psychosis intervention is to minimize that impact so that the person will move on with life in a positive way. Since psychosis risk syndrome and first episode psychosis usually affect people starting between ages 12 and 25, some key developmental tasks may be directly impacted:

- ✓ Experimenting with and forming an identity
- ✓ Individuating and separating from parents
- ✓ Learning independent living skills
- ✓ Living independently
- ✓ Finishing school
- ✓ Entering the work force and identifying a career path
- ✓ Establishing adult peer relationships
- ✓ Establishing romantic and sexual relationships
- ✓ Starting a family

If these developmental tasks are interrupted, the person will need to return to them later before they will be able to progress developmentally. Also, each member of the family who is directly affected by the symptoms of psychosis risk syndrome or first episode psychosis will likely be affected developmentally. Parents who are preparing to send their young person out into the world can experience their young person needing to be more dependent and may discover the need to provide more direction for their young person, which can cause conflict and stress for everyone in the family.



Siblings may develop a fear of developing psychosis risk syndrome or first episode psychosis themselves and may make different choices in relationships because of their need to cope with confusion, grief, and loss. Please see the section on the EASA website entitled **For Families, Allies, and Young Adults** for additional resources for family members, including specific information for siblings:

<http://www.easacommunity.org/impact-of-psychosis-on-family-members.php>.



Adolescent and Young Adult Identity and Development

What is identity?

Having a sense of identity is a fundamental part of being human. The word identity refers to a person's sense of self. Different life experiences influence a person's sense of self. Those life experiences can include where a person lives, the culture(s) a person belongs to, the kinds of relationships a person has with other people and the world, and many other life experiences. A person's thoughts, feelings, worldviews, values, and beliefs, also influence their sense of identity. A person's sense of identity changes over their lifetime¹¹.



The meaning a young person gives to their life experiences plays a significant role in how that sense of identity develops and grows^{3,5,6}. Meanings are “individuals’ responses when they reflect on themselves in a role, socially, and personally¹¹.” In general, a young person's sense of identity is about how the person sees themselves, the world, and their place in it⁵.

Identity is informed by the role a person plays in society (like child, student, parent, teacher), what groups the person is a member of (such as a sports team, a game club, a faith community, a community group for those who identify as lesbian, gay, bisexual, transgender, or queer), and the unique characteristics of each individual. People have different identities at the same time (for example: a parent who works in the school system, and volunteers at a local food kitchen could identify as: parent, teacher, and community volunteer).

When individuals go through changes in life their sense of identity is affected^{5,11}.

What is happening to a person's identity during adolescence and young adulthood?

This stage of life is when identity development undergoes its' most concentrated and rapid growth. Most of the life experiences a person has during this time influence how someone perceives and shapes their sense of who they are as a person. An adolescent's sense of identity and the meaning they give to their identity (for example: I am likable person) has been shown to influence the positive development of sense of wellbeing. Having a valued and positive sense of identity during difficult times in adolescence can help protect the young person from the potential negative consequences of those difficult experiences. This happens when a young person can go through the difficult experiences and develop



an increased sense of purpose about who they are as a person and grow from the experiences⁴.

Typically, adolescence (ages 14-18) is a time when a person is exploring their sense of identity and how that sense of identity influences their life choices (like in friendships, hobbies, dating choices, spiritual and faith preferences, etc.). During young adulthood (ages 18-25) what the individual discovers about who they are when they were younger starts to get even clearer and more refined.

The growth of a person's sense of identity involves a lot of reflection and meaning making. A person's interactions with their larger social, physical, and economic surroundings inform and influence the sense a person makes of who they are becoming as a person^{3,4}.

What is different for young people who are developing their sense of identity and experience psychosis?

Young people who experience psychosis risk syndrome or first episode psychosis, similar to their same age peers that do not experience these conditions, are developing their sense of identity. That includes having the same kinds of experiences, reflections, and meaning making processes. What is likely different for young people who experience these conditions and are developing their sense of identity, is that they have new and unexpected life situations to make sense of and include in who they are becoming at the same time as navigating the typical questions, concerns, and experiences as their same age group peers.

Young people who are developing their sense of identity and experiencing psychosis risk syndrome or first episode psychosis are likely to be more vulnerable to having that sense of identity influenced by their experience of stigma and social judgment. Developing psychosis risk syndrome or first episode psychosis can be a significant change in a young person's life and can influence their sense of identity and beliefs about who they are as a person¹.

These young people are vulnerable to developing a sense of identity that is stuck, or does not allow them to reflect, make meaning, and grow into the person they can become. In order to account for that vulnerability, the people around the young person need to find ways to help the young person make sense of their experiences in a time and way that

fits for the individual, as well as help protect them from the negative consequences society and other people's judgments can have on their emerging sense of self. The personally validating incorporation of experiences into a young person's sense of identity can significantly promote the integration of these growth enhancing and growth limiting experiences



(including symptoms, negative experiences with other people and social institutions) into their emergent sense of self, in ways that allow the person to become who they truly are^{3,4}.

What can we do as family members and supporters to support the growth of a healthy sense of identity in our young person?

- ✓ Know that your concerns are shared by other family members who have a young person who has developed these conditions.
- ✓ Learn about typical identity development in adolescence and young adult life stages and what helps young people learn and grow into having a healthy sense of identity.
- ✓ Ask questions about your young person's life, for example their hopes and dreams for the future, friends, intimate relationships, spiritual and religious beliefs, worldviews and their values.
- ✓ Learn about stigma and why it exists.
 - Let the young person you are supporting know that you will work to accept them for who they are and help them feel comfortable, by listening without judgment, to their experiences, thoughts, beliefs, and worldviews.
 - Let your EASA teams know when you and your young person have a sense of being welcomed for who they are, and when they do not. This gives the team a chance to adjust and correct whatever interactions sent the wrong message. You can practice this in your personal relationships too!

What can we do to protect our young people in EASA from stigma?

Understand Stigma

It is important to define the word stigma before we go further into examining how to help make experiences of stigma less stressful.

Stigma is a term used to describe social interactions that lead to the exclusion of a person from their typical social groups. When an individual and/or groups of individuals are perceived or identify as different from the most accepted groups of people and/or social institutions (like movies, the media, schools, and others) they are vulnerable to experiencing stigma.

For example, a teenager identifies as atheist and lives in a community where everyone else identifies as a specific religion; or if a group of teens identify as “Goth” or “Emo” and they attend a school where their peers identify everyone as mainstream.

Over time, without help to avoid doing so, people can internalize stigma. Internalizing stigma is not always obvious to the person having that experience or to other people. It can be seen in a person's thoughts, beliefs, behaviors, and emotions. An example of this is: My sexual orientation is bisexual. I must have been abused as a child. I should not



apply for that job at the local chamber of commerce. I feel sad that I have messed up my life because I am bisexual.

- When someone internalizes stigma it negatively affects their sense of identity.
- Individuals who encounter stigma can lose important social relationships and get excluded from housing, employment, recreational, educational, social, and romantic opportunities.
- A person's difficult thoughts and feelings (such as fear, a sense of protectiveness, anxiety, beliefs about having done something wrong to cause symptoms, guilt) and concerns related to stigma can lead to that person and/or that person's family not seeking the mental health services they might need.

Stigma happens in social relationships

- Stigmatizing messages can be communicated in conversations and in unspoken messages like body language, facial expressions, and tone of voice.
- It is common for a person or group of people to unintentionally send individuals with differences stigmatizing messages.
- Mental health care providers, from counselors to psychiatrists, can unintentionally send stigmatizing messages to their clients.

Problems stigma might create for young people with psychosis risk syndrome or psychosis:

- Young people's central developmental task or main 'job' during adolescence and young adulthood is to develop their sense of identity.
- In order for young people to develop a sense of identity they need to be involved in life activities that help them better understand who they are as a person in the world.
- It is important for young people to have opportunities to explore their similarities and differences in social relationships and with social institutions that are unlikely to judge or will not judge them based on their different experiences.
- Stigma poses a major risk to the holistic process of identity development for these young people.
- Young people with these conditions are vulnerable to turning experiences of stigma into harmful messages about their identity.
- Friends, family members, allies, mental health providers, and social institutions can make a difference in the identity experiences of these young people.



Disclosure

What is disclosure?

Disclosure describes the, skills, decision-making, thoughts, and experiences that go into an individual's decision to share personal information about who they are, that could lead to acceptance or judgment.

When does disclosure happen in my life?

You probably disclose personal information a lot in your life. That can happen when you are talking with friends, your family members, people who you meet in your community, on social media platforms, and in school or at work.

Young people often evaluate whether or not to tell their parents personal information about their lives on a regular basis. Many young people make these decisions based on the sense they get inside and their experiences of how supported or judged they felt after they shared personal information with their family members. These kinds of choices are common and typical for young people to make during this time of life.

Young people probably evaluate most of their relationships to determine if friends, peers, and other social, work or school groups, will accept or judge them based on the personal information they share.

When does disclosure happen in EASA?

When you first meet someone from your EASA team they probably asked you and your young person questions about your interests, hopes, life dreams, and goals. This EASA team member probably also asked you about challenges you see your young person having in school, at home, with mental health symptoms or unusual experiences, and how those challenges came about or started.

The closer anyone, including an EASA team member, gets to learning more about personal information that could lead to you having a sense that you're getting accepted or judged, the more you or your family member, might evaluate whether or not you can trust that person to accept you without judgment.

The good news is EASA team members know that sharing personal information requires that they support you and your family feeling trusted and heard for what matters to you in life and the kinds of experiences that are bothering or concerning you and your family. Trust takes time to build. That means it is okay for you and your family to go at your own pace in sharing personal information. That way each of you can evaluate for yourselves, how much or little to share at any given meeting with your EASA team members. It is also normal to have different levels of trust with different people. That might stay the same with all your EASA team members, and that might change over time. All this is part of making decisions about sharing personal information with people you have decided you can trust, and protecting yourself from feeling judged.

EASA teams rely on learning about you as a person while also working to understand your young person's mental health experiences, challenges, and the symptoms they are having that brought you to EASA in the first place. Your EASA team wants to gather



information from you and your family in a respectful manner and will often ask permission to see if there is other information healthcare professionals or schools have gathered that could give them helpful information to try to avoid asking you and your family member to repeat yourself, which can be stressful for many people.

EASA team members anticipate that disclosure will happen during the entire time you and your family are in EASA, as well as beyond your time in EASA.

Is disclosure unique to us because we are in EASA?

Great question. Disclosing information about mental health experiences, including symptoms of psychosis risk or psychosis for the first time, usually happens when a young person has found someone who they can trust as the 'right' person to talk to without having a fear that they or their family member will be judged.

About young people in general:

A young person's decision to disclose their experiences of psychosis risk syndrome or psychosis, involves 'reading' other people's body language along with hearing the words they use, and how they use them, (like the tone of their voice and how their body posture changes when you talk to them), to decide whether or not to trust that person with more personal information. Young people evaluate each relationship to see for themselves how open and interactive they sense the other person seems to be.

Trusting another person to disclose personal information can happen quickly or take time, and how long that takes depends on each individual. Again, many young people are looking for an internal sense about the risks and benefits of sharing sensitive information. Young people who have some confidence in their ability to express themselves well using their words might be more likely to share personal information sooner.

A few takeaways:

- ✓ Disclosure relies on trust that is relationship specific (that can be a relationship with one other person or a group of people, including a family member or friend).
- ✓ Trusting someone takes time, even in the best of circumstances. When it comes to sharing personal experiences that could lead to feeling judged, trust might take even longer to build with another person.
- ✓ EASA relies on people disclosing personal private information. EASA teams have time to get to know you and earn the privilege of you and your family trusting them as individuals and a team.
- ✓ Young people evaluate other people, including their parents, for a sense of openness and nonjudgmental stance when deciding to share personal information.
- ✓ Self-confidence in personal communication skills, combined with a perception that the other person is open and receptive to whatever is shared, can improve young people's sense that making a personal disclosure is going to be of benefit to the young person.
- ✓ Helping your young person identify what specific spoken and unspoken cues they get from other people to tell them they can trust that person with more personal



information, is probable helpful. This includes friends, teachers, family members, and healthcare providers, including members of your EASA team.

- ✓ As a family member, you can practice providing a supportive response to your young person when they share personal information.
 - Many young people will look for signs that they will experience criticism, shame, or get punished, for sharing personal information that might be judged, in order to decide to share or not.
 - Your young person and or a trusted EASA team member can help you identify specific strategies you can use to encourage your young person to feel confident that they will be supported and not judged when they share personal information.
 - Some of these skills might come easily to you and some might be hard to develop. Pace yourself and, with the right support, you will learn how to do this with your young person.
- ✓ Getting support from people in your life that you identify as trustworthy can help reduce the stress of sharing personal information and reduce your stress overall. Many family members find these relationships in their existing social networks, groups made up of family members with shared or similar experiences facing mental health challenges, and with other family members involved in EASA.
- ✓ The 'right' people are out there to talk about personal experiences of raising a young person experiencing psychosis or at risk of developing psychosis.



Why does knowing about disclosure matter to me?

EASA team members ask you, your young person, and your family to disclose personal information. We talk about mental health symptoms, diagnoses, and private experiences related to both. It is important to know that needing to take time to share this information is common and that having different levels of trust with different people is common. You and your young person have the right to disclose what you feel comfortable sharing at a pace that works best for you.

Keep in mind that you might have differences about disclosing information to different family members. Getting support around making decision about whether to share or not share certain personal information will reduce stress for everyone.

It will help you and your young person to develop skills and support that allow you to make disclosure decisions that fit for you during EASA, as well as after you complete the program.



What is judgment about psychosis risk syndrome or psychosis called?

This kind of judgment and exclusion is called stigma, and as discussed above it can be emotionally and psychologically hurtful. It comes from other people having a lack of knowledge and unfounded fear resulting in prejudice and hurtful behavior⁹.

Experiences of stigma and fear of stigma often leads to young people not disclosing personal information about early signs of psychosis and can influence their decisions to seek help early on. When a person who experiences stigma—or fears experiencing stigma—discloses personal information for the first time, it is the most difficult disclosure they might face. When these first disclosure experiences go well, it can influence the person's perspective that future disclosures will go well over their lifetime.

Getting support from other people who you decide you can trust to not judge you (or make corrections in their responses and behaviors if they do judge you) can really help reduce the negative experiences that come with stigma.

What kinds of unique considerations come into play for young people who experience psychosis risk syndrome or psychosis?

There are unique concerns that research has identified regarding what young people experiencing psychosis or those who are vulnerable to developing psychosis might be concerned about most when it comes to stigma and disclosure.

- Being viewed differently due to difficulties
- Emotional and behavioral problems treated differently than physical problems
- Anticipation of other people's negative judgments
- Personal sense of being weak or inferior than others
- Concerns about public image changing
- Unwillingness to accept having a different experience from other people and the potential need for more formal support
- Feelings of embarrassment, feeling uncomfortable/concerned/fearful that other people will find out
- Well-intended actions coming across as condescending, making someone feel different and not normal
- Discriminatory actions
- Negative impact of disclosure on peer relationships
- Considering what's 'normal' when it comes to sharing personal information².



Adolescents and Young Adults and Romantic Relationships

This section provides a summary of the current scientific research about romantic relationships in general for young people, and young people who develop psychosis risk syndrome or symptoms of psychosis. The information in this handout can help inform your current understanding about what is typical in romantic relationships for young people the same age as your child or the young person you support who is in EASA. There is also information in this handout about the unique and unexpected concerns and opportunities that can come up for a young person who develops psychosis. Several strategies that you and your family can take to support the exploration and development of healthy romantic relationships in the life of your young person are also included in this handout.

**There is no current published research available about non-cisgender or non-heterosexual individuals who also experience psychosis and how those individuals negotiate and build romantic relationships in ways that are similar to and different from their cisgender and/or heterosexual peers.*

What are some common experiences for adolescents and young adults about romantic relationships?

Developing, being curious about, and experiencing intimate and romantic relationships during adolescence and young adulthood is common. Romantic relationships have a range of personal and social benefits for young people⁹. Those benefits include adding meaning to a person's life and help strengthen their sense of independence and growth¹⁰. Healthy intimate and romantic relationships offer young people and opportunity to establish a valuable sense of connectedness to a person or people outside their family group. Romantic relationships also influence a young person's growing sense of identity^{9,10}. Feelings of fearfulness about rejection by a potential intimate partner and not having the desired confidence to approach a person of interest to flirt and date are common concerns young people in general have about intimate and romantic relationships⁹.

What promotes the likelihood that young people will experience beneficial growth from their romantic relationships?

Here is a list to get started of the kinds of relational experiences and interactions young people have in their social lives that can positively influence their romantic explorations:

- ✓ Experiencing a sense of closeness and feeling supported in relationships with parents, siblings, and caregivers
- ✓ Having opportunities to observe and be part of healthy (non-abusive) conflict and its resolution
- ✓ Forming and maintain trusting relationships with friends
- ✓ Developing and practicing relational skills to share differences in trusting relationships



- ✓ Norms in peer group that establish and support the kinds of relational experiences described in this list.

What kinds of parenting styles and approaches can I/we consider to support healthy romantic relationships in our young person?

Choices about parenting your young person have many unique and specific variations that reflect you and your family's values, beliefs, worldviews, and culture. There is research about general parenting styles and approaches that you can consider adding to your current parenting approach to better support your young person in EASA.

PARENTING to support healthy relationships

Approaches to consider:

Taking an authoritative parenting style—setting clear limits with your young person about their dating life without controlling their dating life, i.e. Monitor the child while simultaneously respecting the child's boundaries.

- ✓ This approach, when used in the earlier teen years, might reduce the likelihood of a child's future victimization in later adolescence and young adulthood.

Ensuring that you treat the young person in your life who is interested in or chooses same gender romantic partners equally as you would treat young people who are interested in or choose partners that have a different gender from their own.

- ✓ Help to identify safe places where they can meet and be intimate without fear of being targeted or victimized.

Source: www.actforyouth.net

What should we be thinking about in regards to romantic relationships when we support our young person who is involved with EASA?

Keep a developmentally informed perspective!

What does developmentally informed mean?

Developmentally informed means taking into consideration what is most commonly occurring for people of the same age as your young person/child while also considering unique and unexpected situations and needs that come with developing psychosis.

What about for romantic relationships, specifically?

There are experiences young people in EASA probably have that are similar to or the same as their peers who do not experience these conditions *and* there are probably unique needs to evaluate and skills to develop. Young people who experience psychosis risk syndrome or psychosis are likely to share similar desires and hopes as their peers without these conditions, and to develop intimate and romantic relationships. Your young person is likely facing new and unexpected challenges while they explore, pursue, and establish their romantic relationships.



Talking about what is typical and what might be uniquely associated with having psychosis risk syndrome or psychosis is likely to help support your young person's exploration of the kinds of relationships they desire with a reduced sense of stress and increased confidence^{7,8,10}.

What might be unique for my young person?

There are probably ways in which romantic relationships can contribute to the healing and growth that young people in EASA are focusing on. There are also some challenges to consider evaluating and planning for with your young person^{8,10}.

Potential benefits of romantic relationships for young people who experience psychosis risk syndrome or psychosis:



- ✓ Strengthen sense of being included in the community
- ✓ Increase social support and sense of reciprocity between individual and other people and/partner
- ✓ Help develop and maintain vital social skills
- ✓ Protective against relapse due to increased social support
- ✓ Continued development of sense of autonomy (which is a typical developmental focus for this age group)
- ✓ Increase sense of connectedness⁸

Potential challenges in romantic relationships for young people who develop psychosis risk syndrome or psychosis:



- ✓ Inability to find a good fit in another person
- ✓ Lack of needed self-confidence to be in a romantic relationship
- ✓ Reduced access to money to pay for costs that can come with romantic relationships (possibly: dates, transportation, gifts, etc.)
- ✓ Memories and experiences in previous relationships that were traumatic or stressful⁸

Potential concerns in romantic relationships for young people who develop psychosis risk syndrome or psychosis:



- ✓ Thoughts and feelings associated with the fear of rejection
- ✓ A need for more reassurance than before experiencing symptoms
- ✓ A concern about their partner over influencing them or losing themselves to the relationship
- ✓ A fear of becoming overly dependent on the other person
- ✓ Concerns about something going wrong in the relationship



- ✓ Social messaging that has directly or indirectly told the young person that individuals with these conditions cannot develop or maintain romantic relationship^{8,10}

What steps can we take to try to reduce the concerns and challenges our young person might be facing about their romantic interests?

There is some evidence in the research that helps us answer that question. Keep in mind that really understanding your young person's concerns and developing effective strategies might take some time and problem solving what is unique to each person. Your EASA team can help you and your family address these issues in a way that fits best for you.

Here are specific areas young people that experienced psychosis told researchers they needed more help with in order to pursue romantic relationships in the least stressful way possible*:

- ✓ Developing and practicing skills *to make a positive impression* on a person of interest;
- ✓ Developing and practicing skills *and social behaviors to engage* the person of interest;
- ✓ Developing and practicing skills *to maintain romantic relationships*
- ✓ Learning to recognize the signs of having an increased sense of comfort with these skills and noticing the cues that there is a deepened sense of connection with a potential partner.

*These needs were the same for young people who participated in the study who did not experience psychosis⁸

What specific strategies could I consider taking to support my young person's hopes, needs, and concerns?

Share and discuss educational information about what young people often experience, hope for, and have concerns about, in general about romantic relationships. Use educational information to engage your young person in a conversation and planning for what fits for them and what hopes, needs, and concerns are unique to them.

These strategies might look like:

- ✓ Explore and discuss romantic relationships, their challenges and benefits for many young people in this life stage, together or helping your young person identify a trusted other person to do this with. That could include someone on the EASA team and/or your family's support network.
- ✓ Identify ways that activities and connections that happen in romantic relationships might offer your young person a sense of moving forward in life and provide a supported sense of connection to others. For example, going to the movies or for ice cream with a peer/friend group that includes the person of interest for your young person.



- ✓ Allow young people to give a personal sense of meaning and decide the benefits of these relationships, on their own terms. Encourage disclosure by taking an authoritative but not punitive approach to parenting. Let your young person know what the limits for their dating life are! For example, only going on dates in groups with other people, in certain locations, and the curfew.
- ✓ Support the young person's self-reflection and evaluation of their romantic history and their desires.
- ✓ Validate concerns the young person has about their romantic relationships and being a person that experiences psychosis¹⁰.

How can I/we know if the romantic relationship poses a risk that might be of concern to me/us?

There are unique risks that the research has identified that you might want to become familiar with when it comes to dating, romantic relationships for your young person with psychosis risk syndrome or psychosis. The following is a list to review and draw from as you and your young person, or your young person and an EASA team member or someone in your support network, work to address their hopes, needs, and concerns about getting involved romantically with people.

- Your young person lacks a sense that they can trust themselves or the other person.
- Your young person expresses that they are significantly struggling with their sense of identity.
- There are traumatic and/or difficult interactions between your young person and the person(s) of interest.
- Your young person experiences threats to their sense of self or physical self.
- Your young person describes a sense that the other person(s) are 'using' them in a negative or harmful way.
- Watch for and assess distressing reactions of other people to your young person's romantic interest(s). Evaluate, strategize and plan to reduce the impact of those reactions your young person.

Considerations to keep in mind as you support the development of your young person's romantic life:

Your young person might be experiencing symptoms of psychosis risk syndrome or psychosis that impact skills that they need to use in their social and romantic relationships. Your EASA team can help you and your young person identify and plan for what kinds of adaptations or additional skills they want to develop in order to gain confidence and engage successfully, on their own terms, in romantic explorations.

Here are some areas to consider:



- Social skills associated with reading other people's verbal and non-verbal cues are commonly affected when a person experiences these conditions, which might make reading other people's cues challenging. This cue reading is involved in many social interactions. If cue reading is challenging, then romantic relationships might take longer than expected to develop. Your EASA team can help evaluate for social skills development needs in order to practice and build skills that work for your young person.
- ✓ Any of these challenges experiences could influence a young person's perception of their skills, abilities, and sense of confidence to pursue romantic relationships in a way that is effective for them and the other person.
- Support your young person establishing or engaging in a relationship with a trusted and informed person to allow the skill development and pursuit of romantic relationships now and in the future. Skill building can take time. Practice noticing both the small and large successes. Do what you can to take a developmentally informed perspective to your young person's romantic life.
- Develop strategies to reduce potential risks that come with experiencing stigma might be quite helpful.

Consider getting to know your young person's mindset using the following questions as a guide:

- ✓ What type of people does your young person enjoy spending time with?
- ✓ What does your young person look for in a potential romantic partner?
- ✓ What is your young person's expectations about the relationship and the implications of those expectations?
- ✓ What are the advantages and disadvantages of having a romantic relationship?
- ✓ How do they perceive their experiences as influencing their romantic relationships (Past? Current? Future?)
- ✓ Explore your young person's perception of their peer group, friends, and family members about an existing or potential romantic relationship.

From these types of conversations, EASA can help you and your young person build and strengthen the skills they need and want that can address their hopes, goals, and concerns about romantic relationships¹⁰.

PARENTING Reflection

- ✓ Have you talked about romance recently with your young person? If yes, what did you learn? What did you agree with? What did you disagree with?
- ✓ What are your family's values, expectations, and beliefs about the role of romance in your young person's life?
- ✓ What are your young person's values, expectations, and beliefs about romance?
- ✓ If you are not comfortable with your young person's romantic choices or preferences, who can they go to that is a trusted adult to have these important discussions?



Resources for parents and young people:

National Network of Libraries of Medicine: has a number of different websites with online resources about topics related to adolescent and young adult development, life, lifestyle choices, sexuality, and intimate relationships, plus more!

www.nlm.gov/mar/guides/consumer-health/teens

Parenting tip sheets for talking with your teen about healthy relationships:

www.healthfinder.gov/HealthTopics/Category/parenting/healthy-communication-and-relationships/talk-with-your-teen-about-healthy-relationships

Fact sheet: www.hhs.gov/ash/oah/adolescent-development/healthy-relationships/dating/index.html

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Connections to Others

EASA Family & Friends Leadership Council (FFLC)

The EASA Family & Friends Leadership Council (FFLC), is a group of family members, friends, and allies of EASA participants who share ideas and improvements about the EASA experience. The FFLC Mission is to help families experience the excellence of EASA.

Powered with what they have learned through their experiences in EASA, the FFLC meets regularly to:

- ✓ Recommend improvements to EASA
- ✓ Promote initiatives to help families and supporters during their time in EASA
- ✓ Advocate for EASA in Oregon

Projects they work on help to:

- ✓ Promote awareness in the community about EASA so those who need treatment and support for psychosis get connected quickly
- ✓ Enhance support for families and friends during their involvement in EASA
- ✓ Improve the process of transitioning out of EASA
- ✓ Encourage support in the community for individuals and their families

All adult family members, friends and other supporters of individuals participating in EASA are invited to connect with the FFLC.

There are two ways to connect:

1. Stay informed through the **FFLC Connections Email Group** – we will share projects and initiatives we are working on and invite your input.
2. Join the Leadership Council and attend meetings.

Find the Family & Friends Leadership Council Application in **Appendix G** of this manual.

To get more information, apply for a position on the Council, and to subscribe to the email group, visit: www.easacommunity.org/fflc.php or ask an EASA team member to help you. You can also email easa@ohsu.edu for additional assistance.



Young Adult Leadership Council (YALC)

The Young Adult Leadership Council (YALC) is a group of young people with lived experience and their allies. It is helping to shape the direction of EASA, emphasizing participatory decision-making and peer support.

Uniting the voices and strengths of young adults and their allies to create a thriving community and a revolution of hope!

They seek to guide the direction of the EASA programs by:

- ✓ Providing an experience of healing and growth
- ✓ Creating an outlet for expression
- ✓ Educating and supporting EASA participants and graduates
- ✓ Responding to/ gathering and using feedback
- ✓ Advocating for change

Participating on the Young Adult Leadership Council is a great opportunity for your young person to work with peers on creative projects. It allows them to begin networking with other advisory groups and get involved with what they are interested in. YALC participants receive an hourly stipend and travel reimbursements for meetings and events. As a member of the Council your young person can gain great volunteer experience to build a resume. It could be a gateway to a job as well; the Council has had several job openings presented to them. The Council is always looking for new people, ideas, and projects. Encourage your young person to join us and share what they have to offer!

Find the Young Adult Leadership Council Application in **Appendix F** of this manual.

To get more information or apply to join the Council, assist your EASA graduate in visiting www.easacommunity.org/the-young-adult-leadership-council.php.

Additional Ways to Get Involved

National Alliance on Mental Illness (NAMI) offers conferences and training, and advocates at local, state and national levels for family members. Many local NAMI groups meet regularly in an "official" capacity with important local decision makers, and often being an "official representative", or having an official position by a NAMI group can be very persuasive to local decision makers. Local mental health programs and other public organizations have governance and advisory boards you can join.

In addition to NAMI, there are many ways to get involved in mental health training and advocacy in your community. Ask your EASA team members for information about how to connect with NAMI and other groups. The EASA program is one way to learn more and meet others who have an interest in fostering a proactive, positive, responsive community of support. There are many opportunities for advocacy.



Questions to Ask my EASA Team:

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SECTION 3: TRANSITION



Pathway Towards EASA Graduation

EASA is a transitional program that focuses on early intervention. This means that a young person can be involved in EASA for approximately 2 years. However, once the two years ends, there are many opportunities to stay involved with EASA. In some EASA programs, young people and their family members/friends can continue to be involved in supports (such as Multi-Family Group) after they graduate from EASA. Ask your EASA team members how you can continue to be involved after your young person graduates from EASA. With your permission, EASA programs throughout the state may reach out to you and your young person to ask you to come speak about your experiences in EASA to other families, young people, or people in the community.

Frequently Asked Questions about Transition out of EASA Services

Why is my young person being closed from the EASA program before two years?

There are some situations where a young person will not stay in the EASA program for the full 2 years. This may be because you, your young person, and the EASA team determine that another program would be a better fit to meet their needs. It may be because your young person moves, however, if your young person moves out of the county but remains in Oregon there are EASA programs throughout the state.

Communicate with your EASA team as soon as possible about moving so that they can help you and your young person connect with another EASA team in the county you and/or your young person are moving to, as well as other resources. Many states outside of Oregon now have programs similar to EASA and your EASA team can help connect you to another program or other resources and supports if your young person moves out of Oregon.

When do we start making a plan for my young person's transition out of EASA?

EASA services focus on supporting a grounded, realistic positive view of the future. The EASA team in partnership with the young person, family, and other supports, anticipates what the time period at and after completion of EASA will look like. EASA team members make frequent use of success stories and invite participation by graduates/individuals in recovery in their interactions with young people and family/support system members. Ask your EASA team about how to stay involved with EASA after your young person graduates from the program.

EASA is a time-limited program, and transition planning begins from the start of services. A formal **transition plan** will be completed at least 6 months prior to the individual's transition from EASA. You are an important part of this transition plan. Ask your EASA team about the transition plan for your young person.



Transition Checklist

EASA teams use a transition checklist to help ensure that all areas of need are addressed before your young person graduates from EASA. You and other family members and friends will be involved in conversations about transition throughout your young person's time in EASA. Ask your EASA team how you can best work with them to support your young persons' transition from the program and be involved in the process.

The Transition Checklist includes the following:

- ✓ **Wellness Plan/Relapse Prevention Plan:**
 - Information regarding the young person's strengths
 - Your young person's early warning signs of symptom relapse, specific actions to be taken when the warning signs occur, and a realistic plan that has been tested
 - The name of one or more key individuals who will act as an advocate if symptoms return
- ✓ **Crisis/Safety Plan:**
 - A list of crisis resources for both the young person and their family/support system
 - A history of interventions that have been helpful, as well as those that have not been effective
 - Specific preferences about medications/other treatment strategies
- ✓ **Medical Services:**
 - A qualified doctor/nurse has been identified to provide ongoing care (if needed/desired)
 - A release of health information has been completed and is on file
 - The young person has met and accepted the medical person
 - A copy of the most recent EASA records have been sent to the new provider
 - A plan has been created for the young person to access transportation to appointments.
- ✓ **Counseling/Therapy:**
 - The young person has stated that they would like to continue receiving counseling services and, if so, has identified and met their new counselor
 - A release of information has been signed for the new counselor
 - The family/support network has identified that they would like to continue receiving counseling services, and, if so, has been received at least 3 referrals from the EASA team for possible family counselors



✓ **Medications:**

- If the young person is currently prescribed medication, there is a plan in place for accessing medications, including identifying a prescriber that the young person will see
- A plan has been established to access and pay for medication for the next 3 months

✓ **Treatment Goals:**

- The young person has completed treatment goals or has a clear path to completing them (including housing, educational, and/or vocational goals)
- All goals have been reviewed with the young person, EASA team, and family members/supporters
- Mutual agreement has been established that goals have been adequately met or that there is a plan to meet them in the future.

✓ **Support System Transition:**

- Family members/support system members have been consulted and are in agreement that the young person is ready for transition
- A transition meeting has occurred with the young person, their family members/supporters, and EASA team members where all transition plans were reviewed.

✓ **Choice of Provider**

- Choice of provider matters because of the importance of compatibility, mix of skills, and the need for a high level of trust and communication.
- Individuals and families/support systems should be informed from the outset, and it should be reinforced over time, that they have the choice of which provider they work with, within the limitations of availability.
- Every effort should be made to accommodate individual and family/support system preferences in providers.



Graduation from EASA

The end of your young person's time in the EASA program culminates with a graduation ceremony and/or celebration for EASA participants and their family and friends. This graduation ceremony and/or celebration will be individual depending on your EASA program. It often involves graduates sharing their experiences, challenges, and successes individually or in a group setting. Each program schedules graduation ceremonies or celebrations throughout the year—ask your EASA team about graduation and they will work with your young person, family members, and friends to honor this important transition in a meaningful way.

My young person's graduation date:  _____

At the end of the two years, some EASA programs are able to include participants, family members, and friends in Multi-Family Groups or other ongoing groups. Ask your EASA team if this is possible or, if not, to help you access other resources and supports.

In addition, EASA teams encourage young people and their family members and supporters to share their stories with their communities and/or with individuals and family members and friends who are new to the EASA program. Talk with your EASA team about participating in educational workshops or community education presentations if you are interested in learning more.

Graduation of your young person from the EASA program can bring up a lot of mixed emotions for people. Talk with your EASA team about your concerns and questions and know that your EASA team will always be available for brief problem-solving and check-ins after your young person graduates from the program.



Life Beyond EASA

Although EASA is a transitional service, we are invested in the long-term well-being of individuals and the families/support systems who complete EASA services. In order to maximize long-term success, EASA pursues the following strategies to provide individuals and family/primary support people with the information they need to be effective self-advocates at individual, agency and system levels:



- ✓ offer ongoing opportunities for graduates of EASA to return for educational workshops, support groups, and decision-making committees
- ✓ provide brief problem-solving support if needed
- ✓ request feedback for quality improvement/system development
- ✓ offer consultation and training to professionals and individuals involved in ongoing care and support of EASA graduates
- ✓ integrate EASA graduates into community education and participant education activities

After graduation, your young person will continue with their new providers, as well as be invited to return to participate in EASA events, planning, and development activities.

Staying Connected to EASA After Graduation

There are many ways to stay connected with EASA after the two years end. In addition to being invited back to share your experiences or participate in events, adult family members and/or friends are invited to join the Family and Friends Leadership Council and young adults are invited to join the Young Adult Leadership Council (**See also: Connection to Other Young People, Families, and Friends involved in EASA**). Talk with your EASA team about ways for you to stay connected to your local EASA program or to the statewide EASA efforts.

How to Get Additional Resources and Support from EASA After Graduation

Even though you and your young person are no longer receiving EASA services, EASA team members are available to help with periodic check-ins and brief problem-solving after graduation. Please feel free to reach out to an EASA team member after graduation if you have a question, want to check-in, or need additional resources. In the event of a crisis or urgent matter, or if you need after-hours support, please contact your local crisis team or crisis hotline number.

EASA Team Member Names/Numbers to contact after graduation:



Local 24-hour crisis hotline number:



Additional Resources

Ask your EASA team about additional resources and information. In addition to the written educational materials, videos and other resources on EASA's website (www.easacommunity.org), there are many other places to find additional resources and information. If you do not have access to a computer or the internet your EASA team members can help problem-solve other ways to get the information. Please let your EASA team members know if you need any of these materials or resources in languages other than English or in another format for you, your young person, other family members, or other supporters.

Here are some additional resources to explore with EASA team members, your young person, other family members, or on your own:

Amador, Xavier. (2011). *I'm Not Sick, I Don't Need Help!* Peconic, NY: Vida Press.

Flynn, L., & Shern, D. (2018) *Family Tip Sheet: Helping Understand Services for Persons with Early Serious Mental Illness*. Alexandria, VA: National Association of State Mental Health Program Directors.

The Here to Help project in British Columbia has a free online toolkit that can be downloaded:

<https://www.heretohelp.bc.ca/workbook/dealing-with-psychosis-a-toolkit-for-moving-forward-with-your-life>

Pat Deegan's website (<https://patdeegan.myshopify.com/>) has information that you can access and use on your own, with your young person, with EASA team members, and/or that you can share with family members and other supporters.

Psychosis: A Wellness Approach, by Mary Moller is a highly useful and comprehensive text. <http://www.psychiatricwellness.com>. Mary Moller also has a video about the stages of post-psychotic adjustment: <https://www.youtube.com/watch?v=96yimdWwdo4>

Schizophrenia Society of Canada. (2003) *Learning About Schizophrenia: Rays of Hope: A Reference Manual for Families and Caregivers*. http://www.easacommunity.org/PDF/Rays_of_Hope.pdf.



Questions to Ask my EASA Team:

This image shows a full page of blank handwriting practice paper. It features approximately 20 evenly spaced, horizontal blue lines across the entire width of the page. The background is a solid off-white color, providing a clear contrast for the blue lines. There are no margins, text, or other markings present.

Notes:

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Appendix A: EASA Strengths Assessment

EASA Strengths Assessment

Participant		EASA Team Member
Current Status: What's going on today? What's available now?	Individual's desires, aspirations: What do I want?	Resources, Personal/Social: What have I used in the past?
Daily Living Situation		
Financial/Insurance		
Vocational/Educational		
Social Supports		
Health		



Leisure / Recreational		
Spirituality		

What are my priorities?

1.

2.

3.

4.

<i>Individual's comments:</i>	<i>Team Member's Comments:</i>
<i>Individual's Signature</i> _____ <i>Date</i> _____	<i>Team Member's Signature</i> _____ <i>Date</i> _____



Appendix B: Crisis Plan

[Insert Early Psychosis Program Name]

Fax to _____ at _____

Effective Date _____

CRISIS PLAN

CLIENT INFORMATION

Name _____

Date of Birth _____

County of Residence _____

Phone _____

Emergency contact _____

Phone _____

MEDICAL INFORMATION

Counselor/case manager _____ Phone _____

Phone _____

Provider Agency _____ Phone _____

Phone _____

MH Prescriber _____ Phone _____

Phone _____

Primary Care Physician _____ Phone _____

Phone _____

Person who has a list of current medications _____

Medications that have been helpful in emergencies _____

Allergies/severe medication issues _____

Mental health conditions _____

Substance use issues _____

Other medical conditions _____

Recent psychiatric hospitalization: Where? _____

Date _____

Reason _____



CRISIS PLANNING

When I'm ok, I _____

When I'm in crisis, I _____

In the past I've tried (give date and results of effort) _____

What helps when I'm in crisis _____

What doesn't help _____

Agreements and recommendations:

☐ I would like to request a trauma survivor peer support volunteer.

This information can be shared with the following people and agencies to help me in an emergency

Signed

Date

Signed

Date

Oregon state law allows healthcare providers to share your confidential information to the extent necessary to help you during an emergency. *Oregon Revised Statutes 179.505 (4)(a)*



Appendix C: Comprehensive Risk Assessment

EASA Comprehensive Risk Assessment

Complete during screening and initial enrollment, EASA 90 day reviews, and as needed.

*Individual crisis planning is indicated when there is current or previous evidence collected in **any of the categories** that have potential risk as observed or reported by the individual, family/support system or EASA Team.*

Suicidal Behavior	Individual	Family/ Support System	EASA Team
<ul style="list-style-type: none"> History of suicide attempts, including <i>rehearsals</i> (behavior associated with practicing to die by suicide) 			
<ul style="list-style-type: none"> Perceived sense of burden to others Low sense of belongingness Lack of access to identified supportive people Thoughts and feelings indicating hopelessness 			
<ul style="list-style-type: none"> History of or exposure to suicide attempt of family member, friend, peer, significant other, famous person or other public figure 			
<ul style="list-style-type: none"> Suicidal ideation (frequency and duration daily, weekly, monthly) Intent (wish to die) Plans (when, where, how) Means (reasonable or immediate access to method like guns and other weapons, medications, accidents including driving, accessibility to bridges) 			



Self-Harm Behavior	Individual	Family/ Support System	EASA Team
<ul style="list-style-type: none"> History of self-harm (purposeful hurting of oneself like cutting and burning): 			
Self-neglect: <ul style="list-style-type: none"> Restrictive eating Restrictive drinking Not addressing or caring for physical health needs 			
<ul style="list-style-type: none"> Vulnerability to victimization and exploitation: Sexual (situations that increase a person's likelihood to get taken advantage of sexually) Financial (for example: lending money to strangers, computer scams, diploma mills, pyramid schemes) Social (for example: discrimination in housing, homelessness, employment, community and school activities, overly trusting, recent loss or death including of friendship, family member, etc.) 			

Aggressive Behavior	Individual	Family/ Support System	EASA Team
<ul style="list-style-type: none"> History of aggressive behavior or assault toward family member, friend, peer, or significant other Thinking about hurting other people, animals, or property (frequency and duration daily, weekly, monthly) 			



<ul style="list-style-type: none"> • Intent (wish to hurt others or destroy property) • Plans (when, where, how) • Means (reasonable or immediate access to method like guns and other weapons and accidents including driving) 			
--	--	--	--

Other Risk Categories	Individual	Family/ Support System	EASA Team
<ul style="list-style-type: none"> • Symptom content associated with dying and special powers (for example, ability to fly, hyper-sexual, voices of self-harm) • Delusions (for example not eating due to fear or paranoia of being poisoned) • Mania • Command hallucinations • Insight (individual's awareness that they are experiencing new symptoms of psychosis or clinical high risk) • Recent discharge from hospital or longer-term institutionalization (jail, inpatient care facility, etc.) 			
Other Considerations: <ul style="list-style-type: none"> • Culture (individual and family) • Sexual orientation • Gender Identity • Faith/Spirituality/Religion 			
Symptom related issues: <ul style="list-style-type: none"> • Engagement challenges • Behavioral concerns • Willingness to participate (unready or unwilling to sign a consent for treatment or meet with EASA team member) 			



<ul style="list-style-type: none"> • Family conflict (for example comments that communicate criticism, judgment, significant anxiety or concern) • Risk level of symptoms (command auditory hallucinations, mania, dangerous delusions for example, persecutory) 			
<ul style="list-style-type: none"> • Leaving primary residence without a plan, notifying anyone, or resources to care for basic needs. 			
<ul style="list-style-type: none"> • Substance use (disorder or misuse) 			
<ul style="list-style-type: none"> • Criminal record and legal involvement 			
<ul style="list-style-type: none"> • Impulsive behavior (symptom based, substance use based, aggressive behavior [toward other people, property, animals], unsuccessful attempts to die by suicide) 			
<p>Medications:</p> <ul style="list-style-type: none"> • Side effects of medication (weight gain, brain fog, lactation, fatigue) • Adverse reactions to medicine (like akathisia) • History of medications: Useful? Not useful? <p>Medical conditions:</p> <ul style="list-style-type: none"> • Health conditions (for example: lupus, diabetes, anemia) <p>Health:</p> <ul style="list-style-type: none"> • Nutrition • Physical activity level • Access to food • Reproductive health • Sleep • Other 			

Evaluate identified risk items and develop crisis plan accordingly.



Appendix D: Relapse Prevention Plan

<i>Relapse Prevention Plan</i>
<p>Reminder of events or situations that triggered relapses in the past:</p> <ol style="list-style-type: none"> 1. 2. 3. 4.
<p>Reminder of early warning signs that I experienced in the past:</p> <ol style="list-style-type: none"> 1. 2. 3. 4.
<p>What I think would help me if I am experiencing an early warning sign:</p> <ol style="list-style-type: none"> 1. 2. 3. 4.
<p>Who I would like to assist me, and what I would like them to do:</p> <ol style="list-style-type: none"> 1. 2. 3. 4.
<p>Who would I like to be contacted in case of an emergency?</p> <ol style="list-style-type: none"> 1. 2. 3. 4.



Appendix E: EASA Transition Checklist

EASA TRANSITION CHECKLIST

Name: _____

Target date of transition (3-6 month minimum): _____

Person(s) completing checklist: _____

1. Wellness Plan/Relapse Prevention Plan

- a. Is there a current plan: ☐ Yes ☐ No
 - i. If no, who is going to create/update one? _____
- b. Plan identifies strengths: ☐ Yes ☐ No
- c. Plan identifies early warning signs: ☐ Yes ☐ No
- d. Plan specifies actions to be taken by the individual and others when these signs occur: ☐ Yes ☐ No
- e. Plan is realistic and has been tested: ☐ Yes ☐ No
 - i. If no, who is going to review this with the person? _____
- f. The person has identified one or more key individuals to advocate in case of relapse and advocate has a copy of plan or has been offered a copy: ☐ Yes ☐ No

2. Crisis/Safety Plan:

- a. Is there a current plan: ☐ Yes ☐ No
 - i. If no, who is going to create/update one? _____
- b. Does the plan include current demographics: ☐ Yes ☐ No
- c. Does the plan include crisis resources for both the person and their natural support system: ☐ Yes ☐ No
- d. Does the plan include history of effective and ineffective interventions and preferences about medications/strategies: ☐ Yes ☐ No

3. Medical staff:

- a. Has an appropriately qualified ongoing doctor or nurse been identified: ☐ Yes ☐ No
 - i. If yes, is there a current Release of Information on file: ☐ Yes ☐ No
 - ii. Has the person has met and accepted the medical person: ☐ Yes ☐ No
 - iii. What type of insurance does the person have: _____
- b. Has a copy of the person's most recent assessment, medication history and relapse plan been sent to the prescribing medical practitioner: ☐ Yes ☐ No
 - i. If no, who will send this information: _____
- c. How is the person going to access transportation to these appointments: _____



- i. If this is not known, who will help establish this plan:
-

4. Counseling/Therapy:

- a. Does the person want continued counseling? ☐ Yes ☐ No
- i. If so, have they identified the future counselor: ☐ Yes ☐ No
- ii. Has the person met and accepted the counselor: ☐ Yes ☐ No
- iii. Has a Release of Information been signed for the new counselor:
☐ Yes ☐ No
- b. Does the natural support system or family want continued counseling:
☐ Yes ☐ No
- i. Has the support system been given the names of 3 possible referrals: ☐ Yes ☐ No

5. Medications:

- a. Is the person prescribed medications: ☐ Yes ☐ No
- i. Where do they currently access medications? _____
- ii. How are they going to continue to access medications?

- iii. Who is going to prescribe the medications?

- b. Access to medications have been established for the next 3 months
- c. Person knows how to secure future medications

6. Treatment Goals:

- a. Person has completed treatment goals or has a clear path for completing them. ☐ Yes ☐ No
- b. Goals have been reviewed and mutual agreement has been established that they have been met adequately ☐ Yes ☐ No

7. Support System Transition Plan:

- a. Natural support system members have been consulted and are in agreement that the person is ready for transition ☐ Yes ☐ No
- b. Meeting has occurred and transition Wellness Plan and/or Crisis Plan
☐ Yes ☐ No

Participant signature

Date

EASA Team Member signature

Date



Appendix F: EASA Family & Friends Leadership Council Application

Family & Friends Leadership Council INTEREST FORM

Contact Information

Name: _____

Email: _____ Phone: _____

Address: _____

City: _____ State: _____ Zip: _____

Preferred method of contact: call email text

Is your loved one:			
Currently in EASA <input type="checkbox"/>	For how long? _____	County: _____	
Graduate of EASA <input type="checkbox"/>	Year completed _____	County: _____	
Please check all you've attended:	<input type="checkbox"/> EASA Multi Family Group	<input type="checkbox"/> EASA Educational Seminar	
	<input type="checkbox"/> NAMI Support Group	<input type="checkbox"/> Other Family/ Friend resource: _____	

Is there any assistance that will help you to participate?	

Would you be able to make a 6-12 month commitment? <input type="checkbox"/> 6 month <input type="checkbox"/> 12 month	
Do you speak any language(s) other than English? _____	
Would having an interpreter help to make your participation a better experience for you? Yes <input type="checkbox"/> No <input type="checkbox"/>	
Meetings will likely take place every other month or more frequently if the group chooses. As we aim to achieve statewide participation, we plan two initial kick-off meetings this fall (one in Portland metro area and one in Grant County). Additional locations will be organized later next year. Please check which location is closest to you:	
<input type="checkbox"/> Portland Metro	<input type="checkbox"/> Central Oregon (Grant County) <input type="checkbox"/> North Eastern Oregon
<input type="checkbox"/> Northern Coast	<input type="checkbox"/> Southern Coast <input type="checkbox"/> Columbia Gorge <input type="checkbox"/> South Eastern Oregon



Interests

- 1. What interests you about being a part of the EASA Family & Friends Leadership Council?**
- 2. What would you have liked to see different about your experience with EASA (either during the program, before or after?)**
- 3. In what ways has EASA been most helpful to you?**
- 4. What skills or interests do you bring to the group?**

Please complete this form and send it to:

Email: magersj@ohsu.edu

US Mail: Julie Magers, OHSU TPC1, 3355 SE Powell Blvd, Portland, OR 97202

**If you would like to complete the form over the phone,
please feel free to call Julie at 503-915-5314**



Appendix G: EASA Young Adult Leadership Council Application

EASA Young Adult Leadership Council Application

EASA is seeking adolescents and young adults who have been involved with EASA to help improve and develop the support available at the local level and throughout the state. The group will prioritize and take action toward the things they feel are most important to change/improve. They will have direct access to local program administrators throughout the state and policy makers at the state level. It will be an opportunity to learn from the direct experience of participants as well as from feedback from others around the state, and to create positive change based on that feedback. Members are asked for a six-month commitment with the possibility of continuing after six months for those who remain interested. Members commit to monthly meetings (in person or by phone). There may also be some subcommittee work and other follow-up depending on what the group decides to pursue. A stipend and travel assistance as needed will be provided to support participation.

How to Apply:

Applications are accepted at any time. Please fill out this form, front and back, and email to Michelle Owens, owensmic@ohsu.edu or mail to Michelle Owens, EASA Center for Excellence, 1600 SW 4th Ave., Suite 900. Portland, OR 97201. If you have any questions call Michelle at 503-725-2293.

Date: _____

Name: _____

Age: _____

E-mail: _____

Home Phone number: _____

Cell Phone number: _____

Mailing address: _____

In which county have you been part of EASA? _____

Are you: _____ Currently in EASA For How Long? _____

_____ Graduate of EASA/EAST Year Completed? _____

Preferred method to contact you: Call _____, Text _____, Email _____



Please Answer the Following Questions:

1. What interests you about being part of the Young Adult Leadership Council?
2. What would you have changed about your experience with EASA (either in the program, before the program or after)?
3. In what ways was EASA most helpful to you?
4. What skills or interests do you bring?
5. What type of assistance will you need to participate?

____ Travel reimbursement ____ Special dietary or accommodations needs (specify):

6. Would you be available to make a six-month commitment? ____ Yes ____ No
Most meetings are currently on the second Saturday of the month from 10am-2pm at Portland State University. Are you able to attend on Saturdays? ____ Yes ____ No



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