

# PARTICIPANT MANUAL



**EASA** Center for Excellence



OHSU



Portland  
State  
UNIVERSITY

SCHOOL OF  
**PUBLIC HEALTH**

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Recommended citation: Sage, M.G. (Ed). (2019). *EASA Participant Manual*. Portland, OR.

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## Acknowledgements

This manual was developed through collaboration with many individuals, including the inclusion of content from the EASA Connections project, interviews and feedback from EASA family members, EASA participants, and EASA team members throughout the state of Oregon, EASA Center for Excellence team members, and with support from the Oregon Health Authority (OHA).

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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 from EASA Participants



Greetings! Welcome new EASA participant! We are the *Young Adult Leadership Council*. We understand your situation and have been in similar shoes. EASA is a statewide program and has served a variety of ages and people of all kinds. Although we may not have experienced the exact same things, we are here to help. We understand this may be a scary or dark time.

**This program is awesome and has helped us tremendously!**

We offer comfort and support and we can also advocate for you. We have group activities, share our experiences and promote the well-being of participants. We are here to build a thriving community and create a revolution of hope. We understand you may be skeptical or unsure about joining the program, but we are here no matter what situation you are in. This program enhanced our lives. The recovery and healing process can be gradual and sometimes frustrating, but your efforts and patience will make the difference.

*"When I got out of the hospital, I thought I was alone, but the people at EASA were there for me, and they will be there for you."*

N. (EASA Graduate & Young Adult Leadership Council member)

*"A diagnosis is scary but this isn't the end of the road. Think of it more as a detour and know that other people have been in a similar place. Don't be afraid to lean heavy on your support system because that is what they are there for."*

M. (EASA graduate, Peer Support Specialist & Young Adult Leadership Council member)

*"I remember being in a dark and confusing place after my diagnosis. Your diagnosis does not define who you are. EASA changed my life and they will help you too!"*

N. (EASA Graduate & Young Adult Leadership Council member)

## Welcome to EASA: What You Need to Know

You are now part of a network of hundreds of young people involved in EASA programs throughout the state of Oregon. At any point in time, there are approximately 400 individuals and families involved with EASA and over 2,000 individuals who have graduated from EASA programs across the state.

### You are not alone.

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, your family, and other support people through this time. The terms used in this manual referring to family, friends, and/or loved ones means any individuals that are important in your life, for example, grandparents, siblings, aunts, uncles, cousins, clergy, coaches, teachers, healers, partners, mentors, and/ or roommates.

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. 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 you and your specific situation. We have a lot of additional resources and information on our website,



[www.easacommunity.org](http://www.easacommunity.org).





EASA programs are provided by local community mental health centers and follow a common set of practice guidelines. These can be found on our website, <http://www.easacommunity.org/PDF/EASA-practice-guidelines-2013.pdf>), or ask any EASA team member for a paper copy. These guidelines are based on international early psychosis standards of practice. Visit our website at [www.easacommunity.org](http://www.easacommunity.org) for additional resources and information, including videos and handouts for you and your family members and supporters.

EASA offers specialized assessment, treatment, and support for both you and your family and friends during a two-year period. The focus is on understanding and treating your individual situation, as well as providing the education and support you and your family and friends need to help you in your recovery and to assist you in reaching your goals.

In the following pages you will find information about EASA that will be helpful to you throughout your time in the program. **This manual is written for you—feel free to write in it and share the information that you find in it with others.**

In this manual you will find:

- Information about EASA’s philosophy and approach
- Orientation to EASA services
- Engaging and working with your EASA team
- Information about confidentiality and protected health information
- Role of family and friends in EASA services
- Making sense of your experiences
- What EASA services look like during the 2-year service period
- Answers to common questions, including what transition process out of EASA looks like
- Additional resources beyond the supports of EASA





- Where do you prefer to meet with your EASA team members (at your home, in the community, in the office, etc.)?



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- Who would you like to involve in EASA services (family members, friends, relatives)? What is the best way to reach out to them?

Name/Relationship: 

Phone number/email address: 

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EASA believes in a “culture of feedback”. That means that your EASA team wants to hear from you! Your EASA team wants to know what is going well and how to adjust services or their approach to make your experience even better. EASA encourages all participants and family members/supporters to give formal and informal feedback about their experiences and how to improve the program.

If you are not sure which EASA team member to talk about a particular issue with, take your best guess. Any team member can bring a question or a particular issue back to the whole team. We would rather you ask any team member, rather than not ask at all because you are not sure which team member to ask.

**Questions to Ask my EASA Team / Notes:**

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## Understanding EASA's Philosophy and Approach

**Everything starts with your strengths.** Your strengths and talents are your best tools for focusing on the life you want. Your EASA team members will work with you early on to learn about your strengths, talents, and abilities and talk about ways to build on these to help you reach your goals.

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 family members and friends make sense of your experiences so that we can work with everyone in a way that best meets their needs, values, and beliefs. Sometimes young people have different perspectives on their experiences than their parent(s) or 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.

**You and your family deserve the information you need to make choices and have your voice be heard.** Members of the EASA team will share the information you want in the way that you want.

**Your feedback is key. 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. Your input is needed to help the EASA team come up with a good plan. Your input is needed to adjust the plan to keep it working.

**EASA is a partnership between you, your family, and your providers.** We believe that participation of family and friends is very important and will talk with you from the beginning about who to reach out to and involve. You and the other members of your EASA team make decisions together in order to get you to your goals. **Communication and making decisions together** are core to what EASA does.

**EASA is about your goals.** Your strengths, goals, feedback, and decisions are an active part of how EASA will help you stay on the path in life you want to be on. EASA genuinely believes that **each person does well with the right supports and opportunities.**

EASA supports you in a **holistic** way. That means that EASA team members work on the goals that matter most to you and your family, including medical needs, school and work, living situation, and relationships.

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





**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 and 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 wants to make it as easy and comfortable as possible for you to participate in services.** Team members are able to meet with you in your home, out in the community, or in the office, depending on your preference.



**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 family members 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 people make choices that may negatively affect their recovery, such as using alcohol or other substances. EASA team members will encourage you to make the best possible choices while continuing to engage you in treatment. There are times that EASA may recommend that you receive 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 your individual needs, your EASA team will work closely with you and your family members and supports 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 is a network.** There are EASA programs throughout Oregon and similar programs throughout the United States and in other parts of the world. If you move while you are in EASA services, or you and your family members 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 family, and your supports for approximately two years, with a gradual transition into ongoing resources after graduation. However, EASA's programs and leadership network works to build long-term community. EASA strives to support our graduates through advocacy and opportunities for long-term involvement.



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

EASA Participant



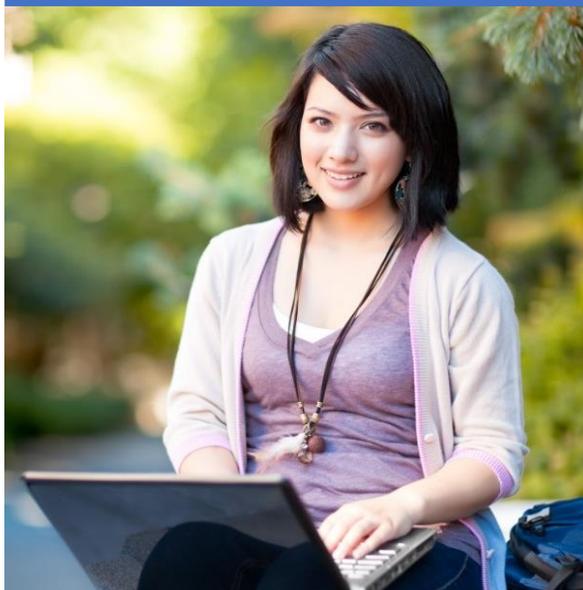
*The EASA team takes the time to listen to you and help you talk about specific areas that you are struggling with.*

EASA Participant



*Working with EASA has made me feel like I'm not alone in my experience.*

EASA Participant



*They'll drive you around, help you job hunt. Now I'm a CNA (certified nursing assistant) and I came here with zero experience.*

EASA Participant



## 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 Center for Excellence team travels 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 with YALC or FFLC (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, PMP**  
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. Craig 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. Craig 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.



**Isabella Orozco**  
Research Assistant

Isabella provides logistical support for EASA C4E by updating staff listings and training records. She provides routine communications and updating related to statewide and national early psychosis team onboarding and training. Isabella also works to provide general support as needed to the team members.



## SECTION 2: THE EASA SERVICE PERIOD





## Who is on my EASA team?

**EASA uses a team approach. Collaboration and teamwork are at the core 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 to solve problems that will support you in achieving your goals. For example, if you want to change your medication or move into an apartment on your own, everyone discusses these topics together to come up with a solution (**See also section titled: What is Shared Decision Making?**).

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 and your family and friends.

The members of your EASA team represent different backgrounds and different expertise. They all bring something different to the table, and they will work together to combine their knowledge and skills to best help you to achieve your goals. Each week, the members of your EASA team will get together and talk about everyone receiving services in the program. These conversations focus on talking about an individual's goals, strengths, and successes, as well as coordinating services to meet the individual's needs. Working with the EASA team includes different team members meeting with you for appointments together, with your permission. It also includes different team members attending your appointments with the licensed medical provider (psychiatrist or psychiatric nurse practitioner) on the team, again with your permission.

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



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

Your counselor will help you to identify and meet your goals, connect you to individuals and resources both inside and outside of EASA that can help you meet those goals, and help problem solve any obstacles that might arise along the way. Your counselor will start by getting to know your strengths and the strengths of your family and community. The counselor will use a variety of approaches and techniques to support you, 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 you achieve your individual and family goals by:

- ✓ Locating resources like housing, benefits, transportation, or support groups
- ✓ Connecting you with other services both within EASA and in the community
- ✓ Working with you and your 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 family, and your support system (with your permission). **No EASA participant is required to take medication to be a part of the EASA program.** However, even if you are not taking medication, you are encouraged to meet with the EASA licensed medical provider (a psychiatrist or nurse practitioner) regularly 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 you focus on wellness and recovery. They will explain any medical diagnoses you have and provide medical information to you and your family members in order to make informed decisions. A psychiatrist or nurse practitioner can help you decide about medications and manage any medications you choose to take. They will help you monitor your overall health and coordinate needs with your primary care doctor. A licensed medical provider will answer questions and provide information to your family members and supports (with your 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 healthcare goals
- ✓ Communicate medical information to your other healthcare providers



## Nurse

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

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

If your EASA team does not have a nurse, the licensed medical provider and other team members will work with you to help you address your wellness needs.



## Occupational therapist

Occupational therapy helps you build the skills and environment you need in order to succeed in work, school, and relationships. Occupational therapists:



- ✓ Learn about the types of environments where you do well
- ✓ Teach and help you develop skills in areas that might be causing problems (for example, help with scheduling, finding activities you enjoy, developing healthy sleep habits)
- ✓ Come up with solutions that you, your family, support system, teachers, and employers might use to make the environments you spend time in be a better fit for your needs
- ✓ Help you identify challenges in work, school, and relationships and build new skills to manage those challenges

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



### **Skills trainer**

A skills trainer can help you integrate learning and build skills specific to your treatment goals. Skills trainers work closely with rest of the team to help you practice and incorporate new skills into your daily life to reach your goals.

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



### **Peer support specialist**

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

- ✓ Draws on their own lived experience to support you in feeling less alone and more connected to others
- ✓ Provides hope and encouragement through their stories of lived experience to you, your family members, and your support system
- ✓ Encourages you to advocate for your needs in a way that makes sense for you
- ✓ Supports you in getting involved in activities you enjoy in the community



### **School and work specialist**

The school and work specialist will help you take direct action to achieve school and/or work goals while working with your school or workplace to make you more successful.

Some ways that the school or work specialist can support you:

- ✓ Help you reach your high school, trade school, college, job, or career goals



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



### **Multi-family groups or single-family sessions**

Sometimes, the best support can come from those who are in a similar situation as you are. In multi-family groups, you and other members of your family or support network get together with other EASA participants and their families and support people to problem-solve challenges. Multi-family groups are not just for family members. They are a place to make and keep connections.

You are not required to attend multi-family group, even if other members of your family choose to do so. However, multi-family groups are a great way to connect with others who have had similar experiences to yours and can be a very important source of support for you, your family members, and other supporters. You may meet people who share your interests (for example, football, religion, fishing, or music), and can plan activities around those interests. You might make a new friend.

The people that you meet in multi-family group offer their perspectives on possible solutions to challenges that people in the group are facing. The unique perspective and ideas that you bring to the multi-family group may help other families and young people find a solution to their challenges. You may share your own advice and ideas, as well as getting advice. Giving back to others can help you make and keep connections.

Ask your EASA team to set up joining sessions for you and your family members 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.



## 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!



## Crisis and Safety Planning

It is important to work with your EASA team from the beginning to create a **crisis plan** (See also **Appendix B**) just in case issues (such as an increase in symptoms or family conflict) arise that may increase stress for you or your family or cause other difficulties. Your EASA team will work with you to help you create a crisis plan and to determine specific situations where you or a family member or support person will need to call the 24-hour crisis line. Your EASA team will let you know which number to call, help you practice what to say when you call, and what information will be helpful to give to the crisis line staff. Some EASA teams provide their own 24-hour crisis services.



If there are specific concerns about your safety (such as concerns about harm or other risks) your EASA team will work with you and your family members and other supports to create a plan to help keep you safe. This will include a comprehensive risk assessment (see **Appendix C**) completed with you, your family members (with permission), and members of the EASA team.

24 Hour Crisis Number:

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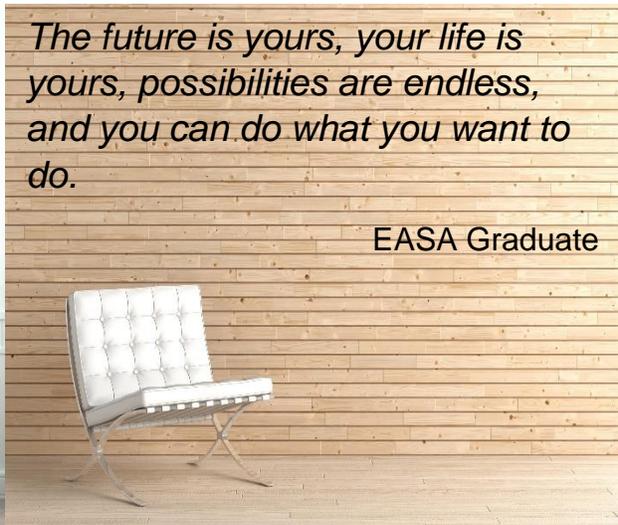
People I can contact when I am not in crisis but need support:

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Phone number/email address: 

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## Role of Connections to Others in EASA Services

EASA believes in the importance of involving family members and friends in your EASA services with your permission. EASA believes that connections to others are important to everyone and want to support and strengthen those connections. With your permission, your family members and friends are an important part of your services with EASA. We encourage young people to talk with their EASA teams about who is in their life and who they would like to involve in their EASA services. Then you and your EASA team can work together to determine how they will be involved (attending some of your appointments with you to talk about your strengths, goals, and challenges, attending multi-family or single family sessions, helping you get to your appointments, etc). EASA services last about two years, and having support people involved in your services with EASA will help to strengthen your relationships with them so that they can be there for you during and after your time in EASA.

Connections improve health and well-being. Connections are a source of emotional support, and can help people in accomplishing their goals. Favorite activities can improve happiness and health. Connections to places and the community helps people feel like they are a part of life. Your connections can help you heal, help you meet your goals, and improve your health and wellbeing. Identifying the connections in your life will make it easier to keep and use them. Your connections are among your strengths. If you identify a connection, you have also identified a strength!

Experiences of psychosis risk syndrome or psychosis can sometimes be disruptive. They can make some people feel distant from their connections, or to lose their connections. Some people have a hard time reconnecting because they feel embarrassed, or because things are harder to do than they once were. **The longer a person is distant from their connections, the harder it can be to figure out how to get them back.** EASA tries to help people keep their healthy connections, even if they need to be put on hold for a little while.



### Keeping it simple

Under any life circumstances, keeping connections is a lot of work. Relationships take time and effort. Activities and going places need planning.

You do not need to work to maintain all of your connections at once, especially right now. The other people in your relationships can take some of the work over, or just wait until you are ready. Your favorite activities will still be there when you want to get back to them. Bigger connections to the world, like school, will also still be there when you are ready for them. **Focus on what you can do right now. Work up to other things in time.**



### Benefits of connecting with people

Connections to people in your life have many benefits. Here are some of them:



- ✓ People you trust can do fun things with you, give you emotional support, and help you feel happy and good about yourself
- ✓ People can help you find information and resources, and give you advice, to help you meet your goals
- ✓ Important people in your life can participate in shared decision-making to make choices about healthcare and services that everyone feels good about
- ✓ Important people in your life can help you identify goals, strengths and challenges, and help you make and carry out a plan to achieve what you want in life
- ✓ People you trust can give you feedback about your decisions, thoughts, and plans, if and when you ask for it
- ✓ People can advocate with and for you to make sure you get the things you want, need, and deserve
- ✓ People can help you communicate in situations when it feels hard to be heard



### Tips for keeping your connections

- ✓ **Many connections will still be there if you need time away from them.** Give yourself permission to take a break from people, places, and activities, if needed.
- ✓ **Focus on what you can do right now.** Work up to other things in time.
- ✓ **Ask others for support in connections.** For example, you can ask your EASA team to plan and do activities with you.
- ✓ **Ask your EASA team to teach the people around you how to better support you in keeping your connections if you need it,** or how to communicate with the people who are important to you.



### Letting others support the connections

Maintaining a personal connection is not all on you. Here are some things other people can do to help support the connection. You can make a copy of these tips and give them to your family members or friends.

- Give me space. My senses may be overwhelmed and having space helps me sort things.
- Encourage me to do a little more, one step at a time, and don't put me down
- Listen to me when I talk and understand I am saying what I am really experiencing
- Keep things calm and peaceful
- Just because I am spending time alone doesn't mean I'm not making progress.
- Keep everybody safe and respected by setting healthy limits
- Don't discourage me from trying things that may seem hard



- Educate yourself about my condition and what helps
- Help me meet other people who have had similar experiences
- Never give up, no matter what
- Take care of yourself and do activities that you enjoy



### Meeting other EASA participants

There are at least 400 other EASA participants across Oregon and over 2000 people who have graduated from the program. Many EASA graduates are interested in meeting people who are new to the program. They like to be supportive, and make connections with others who have had similar experiences.

Some ways to meet other people who have been or who are part of EASA:

- ✓ Go to multi-family or other groups that might be available through your EASA program.
- ✓ Ask the EASA team to introduce you to EASA graduates or others in the program.
- ✓ Participate in EASA events.
- ✓ Suggest an idea for a meet-up, group, or event and work to start one. Ask your EASA team for the contact information for the Young Adult Leadership Council Coordinator, who can help put it together.
- ✓ Tell your EASA team what you are looking for and they can help: coffee, groups, just a text chat with another EASA participant, anything; it's their job to help make connections!



### Making connections through multi-family groups

In **multi-family groups**, people come together with EASA team members to put their heads together and solve problems. Multi-family groups are not just for family members. They are a place to make and keep connections.

- ✓ You may meet new people, including other EASA participants. You may meet people who share your interests (for example, art, football, fishing, or music), and can plan activities around those interests. You might make a new friend.
- ✓ You may share your own ideas and advice, as well as get advice and ideas from others. Giving back to others helps make and keep connections.
- ✓ You may bring a friend. If you want to do this, ask your EASA team how.





## EASA and community activities

EASA programs throughout the state have different activities and groups available. Your EASA team can help you connect to EASA activities and/or activities in the community. For example: workshops (writing, theater, etc.), picnics, hiking, social groups, outdoor groups, opportunities to recommend improvements to the EASA program, peer support groups, or graduation ceremonies.

There are also support and special interest groups in your community. Your EASA team can connect you to advocacy groups like Partners for Strong Minds, Youth MOVE, dual diagnosis support groups, or groups that meet about your interests and activities (reading groups, outdoor groups, gaming groups). Ask your EASA team what activities might be available in your area.

*One of my biggest successes I didn't even expect. As I got deeper into the multi-family groups, and the holistic perspective EASA taught, I found myself getting closer to my family. Now I have a deeper, more satisfying relationship with my family than before I experienced psychosis. My mom and I have a more open and honest connection, and we're closer than ever.*

*-EASA participant*



## What EASA Graduates Say About Connections to Others:

*EASA offered some social events for me to participate in. I went to a graduation and a meet-up at a park. It was nice to meet some of the other EASA members and connect with one of them. We spoke a few times about our experiences, and she told me a few stories about people who had experienced psychosis and been successful. I was also able to talk to two parents who had a kid in EASA and it was good to see their perspective on their own son's experience and how they were mainly just worried about him. I think it made me feel better about some of the problems me and my mom were experiencing at the time.*

– NC

*I wish I would have been more involved [in EASA's events] because they had a lot of fun activities. Don't be shy!*

– Z

*EASA is how I got involved in the Young Adult Leadership Council.*

– L

*Get involved with the multi-family group. If not for yourself, do it for your family.*

– B

*Activities with other EASA participants can be a fun way to meet other people. Playing Frisbee golf or doing crafts let me have an opportunity to talk to others who had similar experiences to mine.*

– D

*EASA's community helps people who've experienced psychosis understand a bigger concept of life outside their immediate selves. While in psychosis, the world can often revolve around ourselves, but the EASA community expands our perspective and allows us to empathize.*

– N



## 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 participant in EASA, it is important to know what the law says and what your legal rights are. EASA honors a young person's desire to maintain confidentiality about their own health, while at the same time recognizing the important benefits of having involvement of family and friends in EASA services.

### 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 you:

- ✓ Understand the treatment you 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 you,
- ✓ A description of other treatments,
- ✓ A description of risks and benefits of each treatment

### Releases of information (ROIs)

Communication from your EASA team to others about information you have shared with the EASA team or information about your specific treatment requires a 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, we understand that you 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 you talking through your concerns and making sure that you 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 you or your legal guardian. For example, if an EASA team member wants to speak with a school counselor or your primary care



physician they must have a signed Release of Information. A signed Release of Information also allows transfer of your medical information to another medical or mental health provider, for example, when you are graduating from EASA your medical information can be transferred to your new provider if a Release of Information is signed.

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 you do not want to sign a full release of information, you may sign a limited release that pertains to specific information (for example, appointment dates and times, treatment goals, specific information about your medication, etc.). It can be very helpful to spend some time talking with your family members, friends, and EASA team members about releases of information and to help you decide what type of information can be shared with whom and for how long.

If you do not agree to have any information released to your family members or friends, the following things can still happen:

- ✓ Your family members and friends can communicate any information they think is important to EASA team members.
- ✓ Your family members and friends can participate in EASA educational workshops and receive educational information from EASA without talking about the details of your specific situation.
- ✓ Your family members or friends 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 you are willing to sign a release of information, freer communication will be possible. EASA teams encourage 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](http://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, or 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 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)**

The work you do with the EASA team is just one part of your life. We all have different responsibilities, activities, and communities that make up our experience. There are times that you might need or want help advocating for yourself in places outside of EASA. You may need support at work or in school, or you may be receiving medical care that your EASA team needs to know about.

With permission, EASA teams also collaborate with other providers involved in your care. Your EASA team is a resource for you in working with other people and services outside of EASA with your permission. This can mean talking to an employer to help you succeed at work, or talking with your school counselor to help school staff understand how to better support you at school. It can also mean working with hospital staff, primary care physicians, family advocates, etc.

EASA teams will not release any information about you to anyone else without permission, except in cases of crisis when information pertinent to your health and safety may be shared in order to keep them safe.

If you need to go to the hospital or a residential treatment center for more intensive care while you are being screened for EASA services or during their ongoing treatment with EASA, your EASA team will continue to be involved in your care with your permission.

If you are hospitalized in another part of Oregon (for example, if there are no available hospital beds in Portland area hospitals, so you may be transferred to a hospital in Bend, or vice versa), your EASA team will reach out to the local EASA team where you are hospitalized to provide support and information (with permission). With permission, your family members and friends are encouraged to continue to work with your EASA team





## Questions and Answers about Confidentiality, Consent to Care, and Rights

### **What can family members tell a provider if I am over the age of 18 have not signed a release of information?**

HIPAA and all other confidentiality rules do not control what you your family members say to a provider. It only controls what the provider says to your family members. EASA team members can receive information to assist in the best care for you without compromising your confidentiality rights.

### **What can a provider tell my family members if I am over the age of 18 and have not signed a release of information?**

Substance use and domestic violence programs cannot tell family members if you are participating in their program. However, providers can talk to family members when it is helpful for your treatment. The provider will talk to you about the benefits of signing a release of information that meets their privacy needs and also supports your family members in knowing when and how to help. Providers must involve family members when there is a threat of harm to self or harming someone else, or if urgent medical treatment is needed.

### **What can I say to my family members when talking about confidentiality and releases of information?**

It will be helpful to talk with your family members about what information they want to know and what they will do with that information. It can be helpful to focus on how you and your family members will work together to stay safe and what you may need to do in case of a crisis. Your family members do not need to know what happens in therapy but it is helpful for them to know what they can do to support you in your progress.

### **What is the goal of signing a release of information?**

The goal is for you and your family members to share responsibility for safety and planning for wellness, harm reduction, and preventing a relapse of symptoms. This is an opportunity to share strengths and concerns and plan 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 you graduate 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 and would to find a time when we can talk." This frames an invitation and 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.



## Starting with Your Strengths

### What is a strengths assessment?

A strengths assessment is a way for EASA team members to learn about you and your family members, and find out what you do well and what resources and supports you have. Sometimes EASA team members will use an activity called a values card sort to discover the talents and abilities of young people and their supports. Strengths assessments should be completed with you, your family members, and EASA team members together towards the beginning of your time in EASA. The strengths assessment is a document that will be revisited and revised throughout a young person's time in EASA, and is also something that you can continue to build on after you complete the program. Ask your EASA team for more information about the strengths assessment, see **Appendix A**, or visit [http://www.easacommunity.org/PDF/EASA\\_StrengthsAssessment\\_Form-I.pdf](http://www.easacommunity.org/PDF/EASA_StrengthsAssessment_Form-I.pdf) to view a copy.

## Making Sense of Your Experiences

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."

It is believed that 5% to 8% of the population experiences psychosis at some point. That's five to eight people out of every hundred you might meet—or at least one in every twenty. That means if there are twenty people on the bus or in a classroom or office, one of them probably has experienced psychosis. There is a good chance you already know people who have experienced psychosis.

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. You may share some things in common with others in the EASA program. However, you also have your own individual experiences, strengths, challenges, and places you are coming from that are unique to you.

Your EASA team honors the importance of each individual looking at their experiences through their own values, beliefs, and perspectives and that of their family members, friends, and/or supports. You 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 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 your eye color and gender, the way you think and perceive is a part of your 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 that people organize and make meaning of their lives. Some people view challenges as an opportunity to grow spiritually. Interpreting your experiences spiritually may help you 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. It is OK to have, or to come up with, your own way of understanding your experiences. This is a normal part of figuring out what the experience of psychosis risk syndrome or psychosis means to you. Talking with your EASA team and others about different ideas, worldviews, and perspectives will help you come to your own understanding of your 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 one's self

#### 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 you 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 you cannot change your genetics, many of the other possible risk factors can be changed. These are called protective factors. For example, learning ways to deal with stress, learning helpful ways to communicate, quitting or reducing use of drinking or substances, reducing work or school stress, or getting stronger 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.

Focusing on connections to people, activities, and places that are positive and help you feel good about yourself are healthy for your mind, body, and spirit. These connections can be with a friend or family member, teacher, provider, co-worker, or roommate, or they can be activities or places, such as a sport, a hobby, a favorite way to relax, or a favorite hike or park. You can participate in these activities or visit these places by yourself, with a friend, or family member, or with an EASA team member.



## How Do I Get a Clear 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. Upon entering EASA services, members of your EASA team will complete an initial assessment with you and your family members and supporters (with permission). The purpose of an assessment is to help clarify whether you have a medical condition, how it is affecting your functioning, and what type of treatment or support may be needed. With this information, you and your family members are able to make informed decisions about your medical care and personal goals.

There are usually multiple people involved in the assessment process, including a psychiatrist or psychiatric nurse practitioner, your primary care physician, a qualified mental health professional (such as your EASA counselor), and, in some circumstances, other specialists such as a neurologist or occupational therapist. In order to complete a thorough assessment, with permission, close friends or family members are usually asked for their input, as they are likely to detect changes in information processing and behavior which sometimes can be challenging for young people themselves to notice. Family members and friends are also a great resource for helping you identify your strengths and skills. The following form was developed by EASA as a tool for families to provide input into the assessment process ([http://www.easacommunity.org/PDF/EASA\\_family\\_input\\_form\\_Nov\\_2012.pdf](http://www.easacommunity.org/PDF/EASA_family_input_form_Nov_2012.pdf)). Ask one of your EASA team members to print a copy of this form for you if you do not have access to it via the EASA website.

Typically, an assessment will include medical tests, interviews, observation and collection of history. The assessment will document changes that can occur in different areas, including sleep, mood, appetite, behavior, and thought processes. As part of an assessment, information regarding medical conditions, injuries, or illnesses, allergies or reactions to medications, substance use, and learning disabilities is also gathered. It is also important to note as part of the assessment process any changes in ability to focus at work, at school, or at home and how this is affecting you and/or your relationships with others.

Another important part of the assessment process is gathering information about who is in your support network, what your strengths are, and what your personal goals and priorities are. In approximately the first one to three months of treatment your EASA team members will work with you to complete a **strengths assessment**, a **risk assessment**, and an **initial treatment plan**, or **service plan**, to identify the goals you want to focus on. Ask your EASA team members about working with you to create these plans. With your permission, EASA encourages family members and other supports to be involved in the creation and monitoring of these plans. See appendices at the back of this manual for copies of all of these forms.

It is not uncommon for the diagnosis process to be ongoing over time. Some of the possible diagnoses require at least six months' observation to confirm. You may be given a "rule-out" diagnosis, which means that additional observation or testing is needed to determine whether this diagnosis is correct. You are encouraged to ask questions and talk with your EASA team about your diagnosis. Usually a preliminary diagnosis is made from the first interview, confirmed within the first 1-3 months of treatment, and revisited periodically throughout treatment. All individuals receiving medical care will receive a

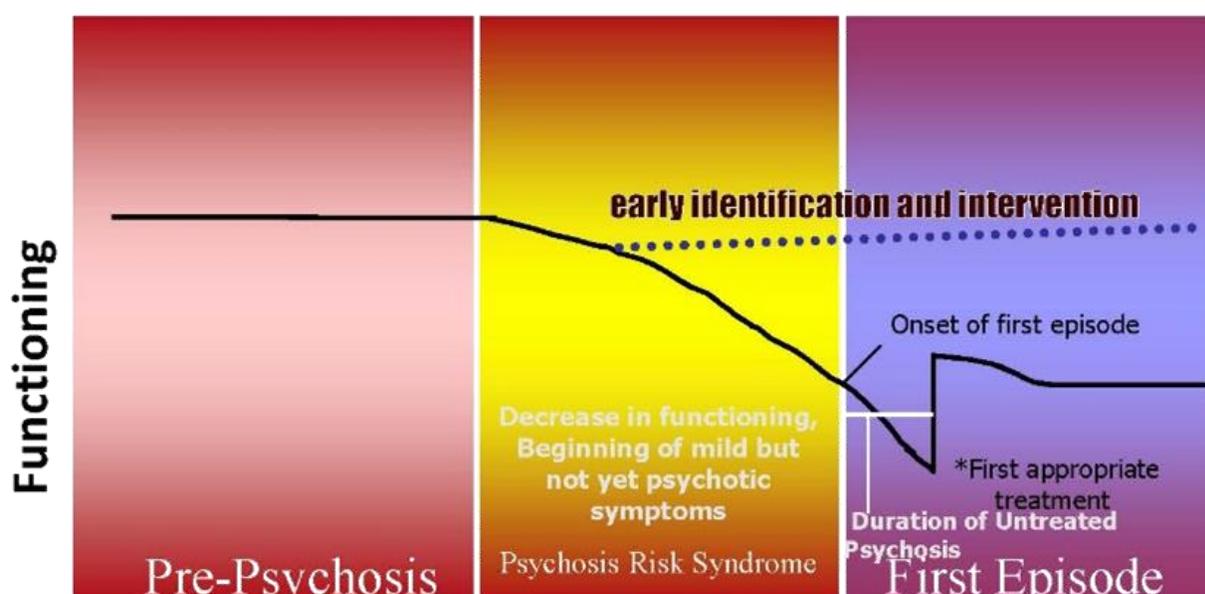




## Psychosis Risk Syndrome

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. Thinking and other challenges can occur during the psychosis risk phase as mild symptoms begin and evidence suggests that intervening at this phase can reduce the intensity of symptoms and/or improve young people's ability to participate in school, work, and life.

### Phases of Psychosis

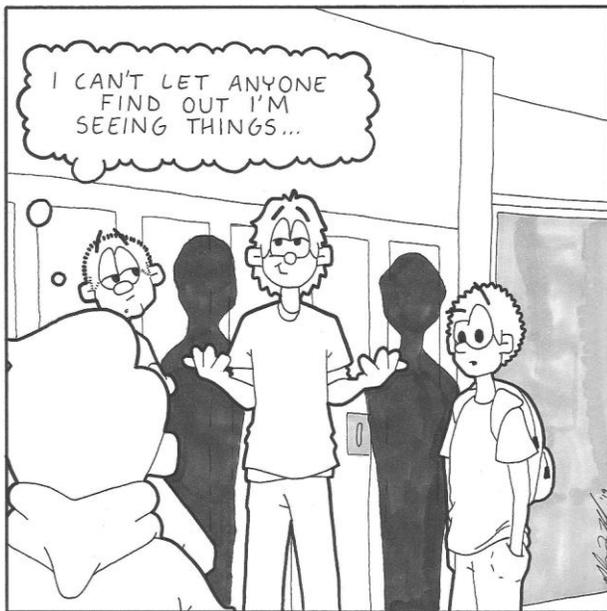


McGlashan, 2001

**SAMHSA**  
Substance Abuse and Mental Health  
Services Administration

EASA uses a specific, detailed tool called the Structured Interview for Psychosis Risk Syndromes<sup>12</sup> (SIPS) to determine if someone has psychosis risk syndrome. It is important to note that even if the SIPS interviewer diagnoses a psychosis risk syndrome it does not mean that a person will develop a first episode of psychosis. It only means that they may be at risk of developing one of these conditions. If a SIPS is completed with you and it shows that you are at risk for developing one of these conditions, don't worry—programs like EASA have shown success in supporting young people who have been diagnosed with psychosis risk syndrome in staying on their life path and reaching their goals. The treatment you receive with EASA will be focused on your goals and to help make sure things do not get worse for you. Psychosis risk syndrome is not a formal mental health diagnosis and it may be difficult to find information about it. Please talk with your EASA team about any questions you have regarding psychosis risk syndrome.





CHANGES IN HOW THINGS LOOK AND SOUND

WHAT'S GOING ON WITH THIS COMPUTER?!? THE SCREEN DIDN'T LOOK ALL WAVY BEFORE.



JAAA000B, III'M COOONCEERRRNEED AAAB000UUUT Y000UUURR GRRRAADEES.



ODD THOUGHTS OR BEHAVIORS

WHAT IS THE MEANING OF LIFE? AND CAN WE REALLY KNOW THE MEANING IF WE DON'T KNOW HOW IT IS TO BE MEASURED? DO WE MEASURE BY WEALTH? OR BY ACTION? OR, DO WE MEASURE BY THE QUALITY OF OUR RELATIONSHIPS?

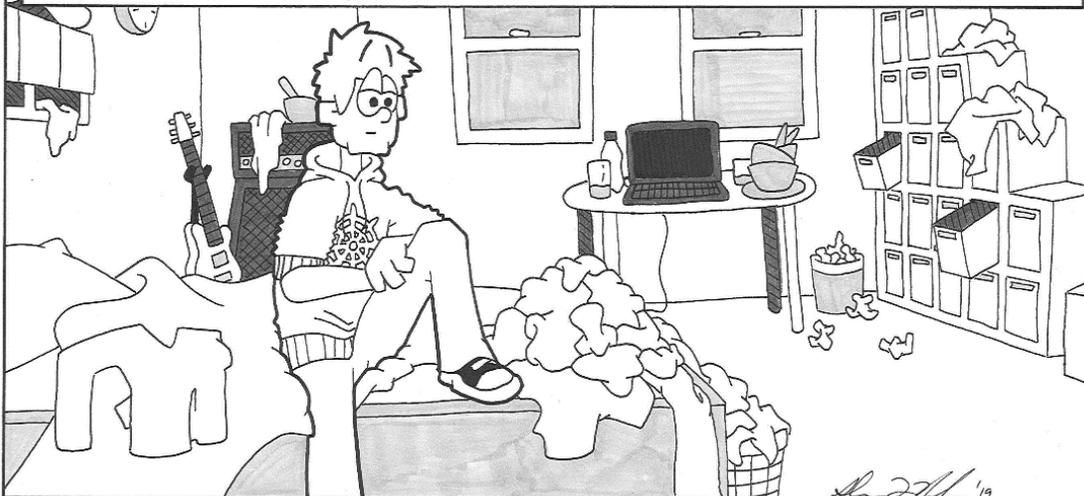


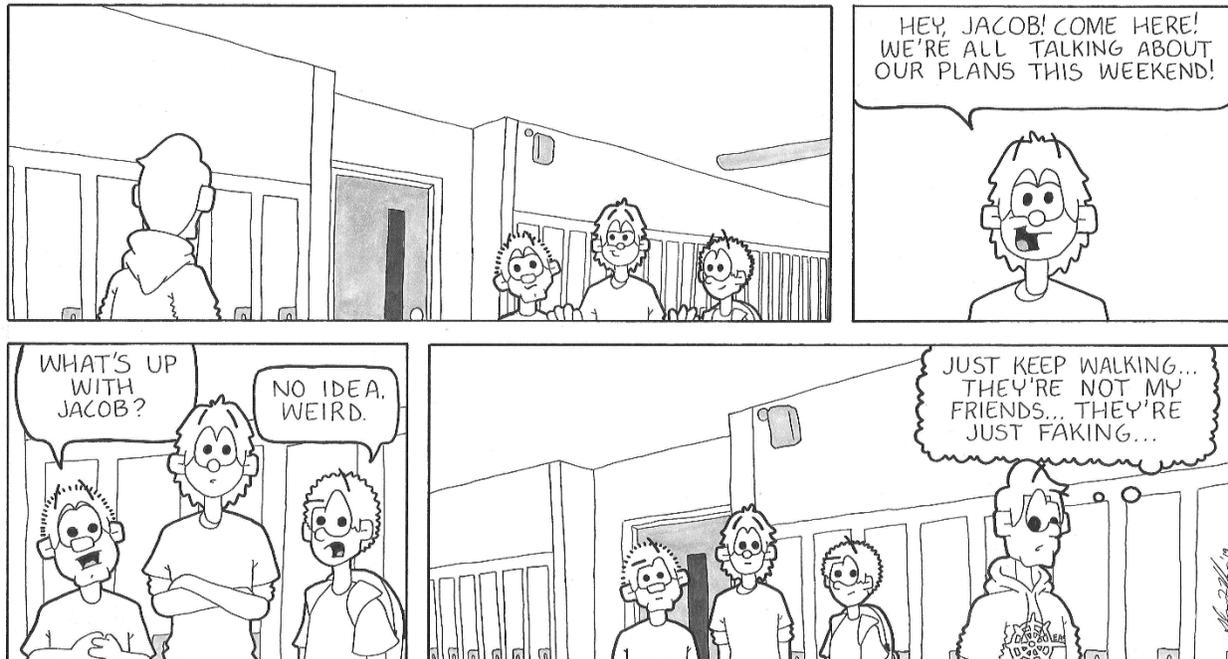
LACK OF EMOTION

HUH, I USED TO GET SO EXCITED PLAYING THIS GAME.



POOR PERSONAL HYGIENE





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. In most situations, symptoms of psychosis risk syndrome start gradually, but are **new and uncharacteristic** of your experiences and feelings.





## First Episode Psychosis or Bipolar Disorder with Psychosis

Psychosis is a condition that 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). Programs like EASA have shown success in supporting young people who have had experiences of psychosis stay on their life path and reach their goals.

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, 5<sup>th</sup> edition<sup>13</sup>) 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.

Diagnoses can, and sometimes do, change during your time with EASA, or after you graduate. It is important for you to talk with your EASA team members about any changes in symptoms you experience during your time with EASA.

Some examples of possible primary diagnoses that you may receive before you enter EASA services, during your time in EASA, or after you graduate 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.



## Recovery in First Episode Psychosis or Bipolar Disorder with Psychosis

Getting back to life after experiencing psychosis can be challenging, and is often gradual. Sometimes people have to re-learn everyday things, like talking or making a sandwich. Some people are afraid of bad experiences happening again, or are embarrassed by people who saw them when they were experiencing psychosis. Getting back to life is a process, and is unique to each individual. It is often gradual, and is not a linear, step-by-step process. However, there are some typical experiences that are described below. These stages may come in small steps, and some may happen at the same time or more than once. **Recovery looks different for everyone.**

- ✓ **People may spend quiet time alone on the couch or in their room processing what has happened.** This is not laziness; it is working toward new understanding of one's experiences. This is when people work out what has changed and what that means for them.
- ✓ **People start wanting to interact with others.** They start experimenting with how to communicate even though they may still be having a hard time. From their interactions with others, they gain more understanding about what has changed, and start working out how to behave around others.
- ✓ **People try out being in broader social settings like a mall, a church, or a gym.** These are real-world settings with other people, but these are also settings without a lot of personal demands or stakes. In these settings, people fine-tune the new ways to think and behave that they have been experimenting with, and start getting consistency back into how they experience life.
- ✓ **People start thinking about getting back to their life goals in settings where there have bigger demands and higher stakes.** For example, going back to school, getting a job, or getting a new place to live. This is when the understanding, re-learning, and fine-tuning starts to pay off and life begins to get ordinary again.

It is very helpful and important for you and your family members to communicate with your EASA team about any changes you see or experience with regard to symptoms. This information will allow your EASA team to make sure that they are providing the best services to address symptoms and challenges to help you reach your goals. If you begin to experience symptoms of psychosis after a period of time in which you had not experienced symptoms, or if your symptoms become worse, the EASA team will work with you and your family members and supporters to address the symptoms so that you can continue working towards your goals without interruption.

An increase in symptoms of psychosis does not necessarily mean that you will need to go to the hospital, have to start medication, or have to change medications if you are already taking medications. The sooner that you 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** that you, your family, and your EASA team create together is an important part of the process of paying attention to an increase or worsening of symptoms (**See section on Relapse Prevention Planning or Appendix D**).



## What EASA Graduates Say About Making Sense of Their Experiences & Figuring Out Next Steps

*At first, life as I knew it was over and feelings of anxiety overwhelmed me. Sometimes the only time I would leave the house was to attend EASA events. I would sleep up to twenty-two hours in a day sometimes. But with time and patience, and trusting in the process, that changed as I worked with EASA and they worked with me. Progress doesn't always come as fast as you might like it to, but without even realizing it, it did. Even when it was hard to imagine anything working right EASA helped me get on the track to the career and future I wanted to pursue. You can do it too, I promise.*

M., EASA Graduate

*EASA can help you make and meet your goals for the future, and we can help you figure out what's important to you.*

P., EASA Graduate

*You don't have to figure out everything today. You can just focus on tomorrow and go one step at a time.*

A., EASA Graduate





## Other Conditions

Sometimes people experience other differences in thinking or feeling in addition to symptoms of psychosis risk syndrome or psychosis, for example depression or mania. These conditions are also common among people who are not experiencing psychosis risk syndrome or 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 having a bad or sad day. People faced with depression experience five or more of the following things, 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 often associated with appetite changes
- ✓ making a lot of agitated motions like pacing or hand-wringing
- ✓ moving or speaking more slowly than usual
- ✓ feeling tired or guilty for no real 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 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, you may be diagnosed with bipolar disorder. Bipolar disorder is usually treated with therapy and/or medication.



## Sleep Problems

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 things a person is struggling with, like psychosis, much harder.

Some common sleep problems are:

- ✓ insomnia - not being able to fall asleep
- ✓ narcolepsy - being super-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.



## Overview of EASA Services and Supports

The EASA program typically lasts about two years. The first six months are generally spent getting to know you, your family members and supporters, your strengths and goals, and working together to help you get through any major challenges you are facing.

The rest of the program builds on the work you do in those first six months. During the two year EASA service period, as well as after graduation, you will have opportunities to learn about yourself, connect with others who share similar experiences, and gain skills that will help you move into the future that you want.

Treatment with EASA will be specifically tailored based on your diagnosis and your strengths and needs. It can take time, but your EASA team will work with you to get to the most accurate diagnosis and to provide the most appropriate, evidence-based treatment. Although the EASA program lasts two years for individuals with first episode psychosis or bipolar disorder with psychosis, it may last longer for individuals who enter EASA services with a diagnosis of psychosis risk syndrome and go on to develop a first episode of psychosis. Ask your EASA team about how this will work for you if you have been diagnosed with psychosis risk syndrome.

Your treatment with the EASA team may include a variety of services and supports, including:

**Strengths-based assessment and treatment:** Focusing on your positive assets to promote wellness and recovery

**Cognitive behavioral therapy (CBT):** Helping you understand how your thoughts and feelings influence your behaviors. CBT can assist you in coping with stress, addressing grief, and learning new ways to deal with typical life challenges

**Motivational interviewing (MI):** Helping you identify your goals, what may be getting in the way, and helping you reach those goals

**Harm reduction techniques:** Helping you reduce behaviors, such as substance use, that may get in the way of your recovery

**Individual Resiliency Training (IRT):** Helping you reach your goals through a focus on strengths and learning new skills

**Mindfulness strategies:** Helping you focus on awareness of your thoughts, feelings, physical sensations, and environment to ground you

**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, their benefits, and side effects.

There may be other evidence-based treatment that your EASA team members specialize in. Ask your EASA team members for more information about other treatment and therapy that may be helpful to your specific situation.



## EASA Phases of Care

EASA services look different for each person 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. Each phase generally lasts about six months but is very specific and unique to each person:

### **In the assessment and stabilization phase the EASA team will:**

- ✓ Provide outreach to you and your family/primary support system
- ✓ Get to know you and your family/primary support system
- ✓ Provide comprehensive assessment services
- ✓ Assist with completion of recommended medical tests (as soon as possible!)
- ✓ Begin treatment for identified medical conditions, including 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 you and your 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 you and your family will:**

- ✓ Provide more extensive education to you and your family
- ✓ Continue treatment
- ✓ Address adaptation issues
- ✓ Refine and test the relapse prevention/wellness plan
- ✓ Refer for alcohol and/or substance use 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 you and your family will:**

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



**In the transition phase you and your 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 you and your 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



## The EASA Service Period

EASA offers various services and supports to you, your family members, and your friends (with permission) over a two-year period. EASA believes that involvement of family members and friends in services is key to helping you recover and achieve your goals and will work with you to figure out the best way for your supporters to be involved in services. Every 3 months you, your family members and friends (with permission), and your EASA team will sit down together to review goals and progress and figure out next steps in supporting you in your recovery. This is also known as treatment planning or service planning.

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
- ✓ Relapse prevention planning
- ✓ Crisis 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 offering specialized services specific to the needs, strengths, and goals of you and your family, EASA provides many opportunities for participants, graduates, 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: Role of Connections to Others in EASA Services**).



## Educational Workshops

Soon after you join the EASA program, your EASA team will invite you to an educational workshop. In this educational workshop you will learn about the conditions that EASA treats, an overview of treatment options (including medications), and the process of recovery. You will also learn about coping and communication skills and talk about the EASA Family Guidelines. 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 and meet other young people and their family members who are in the program.



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 scheduled workshop is:




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### Your EASA team contact for the workshop is:




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## Multi-Family Groups or Single-Family Sessions

After you attend the educational workshop your EASA team will talk with you about joining 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<sup>15</sup>. 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 (and your family members and friends with permission) to the multi-family group or single-family session process and answer any questions you may have.

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




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### Your EASA team MFG/Single-family Session contact is:




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## What EASA Participants and Graduates Say About EASA's Approach:



“EASA's community helps people who've experienced psychosis understand a bigger concept of life outside their immediate selves. While in psychosis, the world can often revolve around ourselves, but the EASA community expands our perspective and allows us to empathize.”

*N., EASA Graduate*

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

### **Trust.**

The more you trust your team, the more help you can receive. Go to the family meetings, join organizations. As an EASA client I didn't participate in activities during the first year because I felt ashamed about my condition. When I finally started participating, a weight was lifted. I met people who had gone through psychosis, who understood my experiences. Nothing helped me more than being surrounded by people who understood. After some time, I didn't feel ashamed, but empowered to help other people.”

“Working with EASA has made me feel like **I am not alone** in my experience.”

“No matter how dark your experiences are, they can be used as a tool for making positive changes in the world.”

**“You are not defined by your past alone.”**



## What EASA Team Members Say About EASA's Approach:

Something I'd like all new EASA clients to know as they're coming into the program is that often times they'll have heard messages about needing counseling or needing to work with EASA from maybe the hospital or family members, but that's not how we approach our work together. **I see us as just two individuals on this journey together** and the more that we can collaborate and work together the better that we can work at getting closer to the goals that you've identified.

I've done things with people like painted, done collage, hiking, playing music together, things like that.

I've helped people fill out applications, or we've also just sat and played card games or board games which is super fun.

One of my favorite parts about this job is that we get to do so many more things than just sitting in an office and talking.

Coffee or going out to eat is really great, I've also helped people take their dogs for walks or go to the dog groomer, and gone to grocery stores or Goodwill.

I feel like I've learned so much from working with the young people that I see every day in my job with EASA, and **it's really just such a privilege.**



## EASA's Philosophy About Making Decisions

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 needs, concerns, and preferences, and then everyone makes a plan together based on that information. This type of decision making process is called “Shared-Decision Making”, or SDM<sup>14</sup>.

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. This idea can apply to other parts of a young person's life besides healthcare decisions, for example, when working with your EASA team to make a plan for school that respects your needs, values, and preferences, when deciding whether or not to disclose a medical condition at work, whether to live alone or with roommates, or how to remain engaged in school or work after an increase in symptoms, etc.

In this approach, people and their providers communicate with each other and come up with a plan together based on:

- ✓ what is important to the person;
- ✓ mutual understanding of all options;
- ✓ mutual understanding of the pros and cons of each of those options.

**This a way to make an informed choice about healthcare and services that respects both the person's priorities and the provider's experience.**



### What kinds of decisions might need to be made?

During your time in the EASA program, you might need to make decisions with your EASA team, family members and supporters, healthcare provider, or another provider outside of EASA. Here are some common decisions that EASA participants make:

- **What the goals of the recovery plan or treatments are.** For example, is the goal to reduce anxiety or to be able to complete homework on time?
- **What the expected outcomes or end results of the recovery plan or treatments are.** For example, when you take a new medication should you expect better sleep, and if so when and how much better?



- **What specific things go into a recovery plan or treatment.** For example, is being physically active part of it, or medication for anxiety, or maybe career counseling? Or perhaps multi-family groups or supported employment are a part of the plan.
- **Whether or not to use medication, and if so, what kind is the best medication for you.**
- **Which available providers to see.** This means selecting which roles should be on your EASA team; for example, whether or not to add an occupational therapist. It also means that you can fire our clinician and find a new one if you are not a good match.
- **Who will be responsible for making the things in the recovery plan or treatment happen.** For example, will part of the plan be done by an occupational therapist, or will it be done by you?



### Is the decision still my choice?

Making decisions together does not mean giving up what you want or care about. Your needs, values, and preferences are honored and respected. Like self-determination and goals, **just because you have others working with you or supporting you does not mean that you give up your ability to be in charge of your own choices.** You own your body and mind, and it is your choice what your treatment should be. You have a right to:

- ✓ know what your treatments are;
- ✓ know what your treatments are supposed to do;
- ✓ know the possible risks and benefits of your treatments;
- ✓ share in the decision of which treatments you will try and when;
- ✓ share in defining how you will know if your treatments are working;
- ✓ define the goals and outcomes for your treatments. For example, some people may want symptom reduction, but others may simply want to learn how to live more peacefully with their symptoms. Some treatment goals may have nothing to do with symptoms, like making it so that you can go out with friends more often or learn a new hobby.



### Four parts of shared decision-making philosophies

**For shared decision-making to work best, you and your provider should be in agreement about four things.** It can take a while for you to get to know each other well enough to come to agreement. That's okay; this type of decision making can take time to get right, and fortunately there is usually no rush. Take the time you need to tell your side of things and to listen to your provider's side of things and agree on the following:



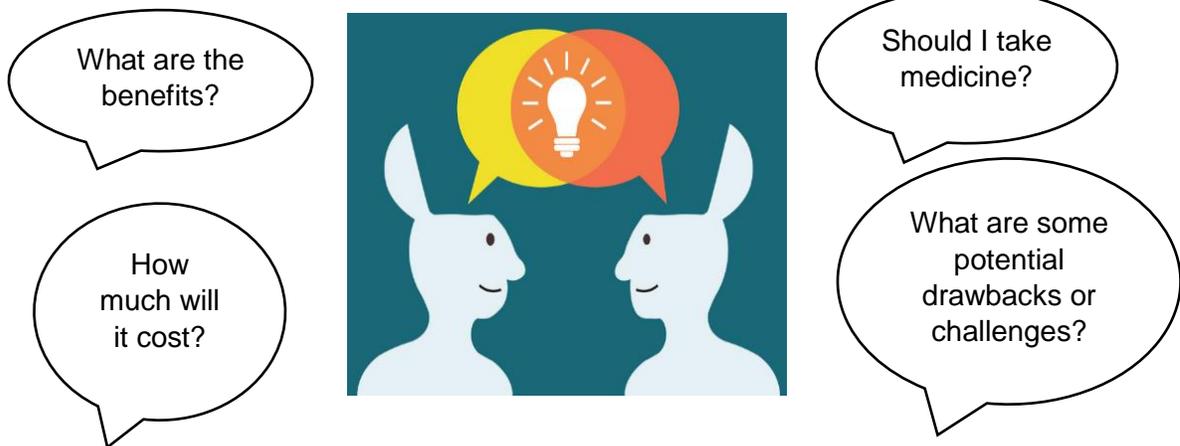
1. **Individual preferences:** This is both your provider understanding your preferences and the things that are important to you, AND you understanding your provider's preferences and the things that are important to them.
2. **Goals:** You and your provider should have a shared understanding of what your treatments are trying to achieve.
3. **Nature of treatment or intervention:** You and your provider should have a shared understanding of which treatments you are trying, and their pros and cons.
4. **Roles of others:** You and your provider should have shared understanding of the roles the people around you play in your treatments. This includes the role of you and your provider, as well as other people in your life, such as family and other providers, other supports, and EASA team members.



### Decision-making, trust, and respect

**In order for it to work for people to make decisions together, participants and providers need to trust each other.** Trust can take a while to build. Sometimes, depending on the people involved, this is difficult, and sometimes it never happens. It's okay to take time to build a relationship with your provider. It's also okay to switch to a different provider if, even after a long time, you can't trust each other (if another one is available).

**In order for this type of decision making to work best, providers also need to be able listen to and respect the person's wishes, and to stand back and let them have self-determination with regard their decisions.** Not all providers are good at doing this. If after time and effort your provider doesn't respect your decision making, it's okay to find a new provider (if another one is available).





*Medication can be very empowering if the decision is truly made by the individual. Pressure can be subtle. The information can be stacked to make it look like the only option. If one option isn't working, it's important to explore others that might. We will make decisions that others disagree with, and it is important for us to be able to be honest and discuss our decisions without feeling shamed, blamed, or threatened.*

EASA participant  
(EASA Young Adult Leadership Council Focal Point article)

*In an EASA treatment team, you will be working towards your overall well-being, and you should try to collaborate and consider other members' perspectives as well as your own. Each person on your team plays a different role which means that people may have differing opinions on what is right for you. Compromise may be necessary including with family members. So just remember that it is all for your future.*

S., EASA Graduate

*It's a big thing—(youth) being able to have their own voice.*

EASA Parent

*One, be honest with your treatment team. If something is not working for you, or you need something new, let them know. You cannot get the help you need if you do not keep your team in the loop. Two, figure out what works best for you. I liked having multiple team members in one room to discuss future decisions; however, you may not like that and rather speak one-on-one and that's okay. If you feel like your voice would be better heard through just one team member, you should go along with that feeling.*

N., EASA Graduate

It can be really important for you to share your perspective of the situation, especially if it's something that makes you feel uncomfortable. I attended a prescriber appointment with somebody that I work with and I thought that the meeting went fine. But I found out later that he didn't feel like it went fine and was really uncomfortable with it. And so once I knew this we were able to make a plan together for how to address those concerns with the prescriber and it led to a better relationship with us and better self-understanding and self-advocacy for him.

Linnea, EASA Team Member

You can help by writing down questions before you have meetings with your provider or your EASA team and letting us know of any side effects or problems you're having, any questions you have, we really want to hear from you about how things are going for you and what's working and what is not working.

Megan, EASA Team Member



## Sharing Your Experiences and Information with Others

In general, the word "disclosure" means to make previously unknown information known. However, the word is also used in a specific way to mean telling someone about an experience or diagnosis of a health condition, disability, or difference, like psychosis risk syndrome or psychosis.

In some cases, disclosure might be of the medical diagnosis you have. For example, in order to get reasonable accommodations, you would need to disclose your diagnosis to disability services at college or university, or to human resources at work (though not to your teachers, supervisors, or anyone else).

Disclosure could just be of some part of your experience. For example, you might tell a friend you haven't spoken to them in a while because you were having trouble communicating (not because you didn't care about them), without naming a diagnosis. Or, you might share an experience you had with a psychology class, when other students aren't being very understanding of what it might be like.

One EASA graduate describes disclosure as a process of "strategic sharing."



### When should I disclose my diagnosis or experience?

Disclosure is very personal. **Different people will make different choices about whether to disclose at all. Everyone will have different boundaries and needs to consider.**

Disclosing can:

- ✓ **Help you achieve your goals.** For example, will you need changes to the workplace to keep a job or extra time on tests to finish school (reasonable accommodations)? Will you need access to services that are only available to people with a diagnosis or experience of psychosis risk syndrome or psychosis?
- ✓ **Help improve a relationship.** For example, if a friend doesn't know, they might misinterpret your behavior as you not liking them, instead of you just needing some time to sort things out.
- ✓ **Make things more or less safe for you.** For example, if you are at risk of losing your job if you don't disclose to human resources, or if disclosure might risk someone hurting you.

### Questions to ask yourself before you disclose, to help decide:

- ✓ What might be good for this person to know about my diagnosis?
- ✓ Will disclosure improve communication and understanding between this person and me?
- ✓ Could my disclosure bring about any negative effects?
- ✓ Is this the best time for me to disclose my diagnosis?
- ✓ How might this person react to my disclosure, and will I be able to cope with the reaction?





## What are some pros and cons of disclosure?

You will need to weigh the risks and benefits for yourself to know what is right for you. These are a few common pros and cons. This is another topic you can talk about with your EASA team.

### Possible Benefits

- ✓ **Understanding, acceptance, and support** - Knowing your diagnosis may help others understand you better, and provide better support. Their understanding can help bring about a sense of acceptance.
- ✓ **Communication** - Knowing your diagnosis may help others interpret the things you say and do correctly. This can help them to communicate with you better.
- ✓ **Accommodations** - If you disclose, you can ask for things to help you access school, work, and the community.
- ✓ **Services and Benefits** - Some services or benefits (such as scholarships or vocational services) might be open only to people who have experienced psychosis risk syndrome or psychosis, or who have another qualifying diagnosis.
- ✓ **Broader Social Change** - The more open people are about something, the more normal it becomes in society. This can help people in the future be more accepted.

### Possible Risks

- **Misunderstanding** - Others may not know much about psychosis risk syndrome or psychosis and may misunderstand what it is or how it applies to you.
- **Misjudging Abilities** - Others may underestimate or misjudge what you can do based on their lack of understanding about psychosis risk syndrome or psychosis.
- **Lack of Support** - Others may not be supportive after finding out.
- **Disbelief** - Some people may not believe your diagnosis if you do not fit their limited understanding of what people who experience psychosis are like.
- **Loss of Confidentiality** - People who aren't bound by law to protect your privacy could tell others about what you disclose. For example, if you tell the person who sits next to you in home room, they might tell the whole class.



## Do I have to disclose at work or school?

You do not have to tell your employer or your school about your experience or diagnosis of psychosis risk syndrome, psychosis, or about any other medical diagnosis you may have.



However, if you want changes made at work or in school to keep a job or stay in school (reasonable accommodations), you will need to disclose. This is because the laws that require businesses and schools to make those changes (the Americans with Disabilities Act (ADA) for jobs and colleges, and IDEA for high school) require disclosure. You do not need to disclose to your boss, teachers, or co-workers however. There is usually someone at human resources or in disability services who takes on this role.

These laws are also designed to protect people with disabilities from discrimination in the workplace or at school. They are supposed to give people an equal opportunity to succeed. These laws are supposed to prevent people from being fired or kicked out of school because of what they disclose. However, the existence of a law doesn't always guarantee it will be followed.

If you are worried or curious about if you should disclose at work or school, talk to your EASA team about your concerns.



### Tips for disclosing

There is no magic formula for successful disclosure, but these tips are ones some people have found useful.

- ✓ Test people out for their reactions to see if they are safe to disclose to. For example, you might mention that you know someone who has experienced psychosis and see if they respond positively or negatively to that idea.
- ✓ State your experience or diagnosis of psychosis risk syndrome or psychosis plainly, and with confidence.
- ✓ Share your strengths
- ✓ Share your challenges and some solutions you are working on
- ✓ Share your recovery plan and what you've accomplished.
- ✓ Remind family and friends that you are still the same person
- ✓ Stay strong if people do not respond in a way that you had hoped for. People often come to understand things better after they have some time to think. Try to be patient and persevere in educating others about yourself and your needs, even if you only do so a little bit at a time.



### What can I do if people who are important to me react badly to my diagnosis?

Some people may react with disbelief, hostility, or other negative feelings. This can be hurtful or even traumatizing. It's important to find sources of encouragement and strength.



Here are some ideas:

- ✓ Seek counseling from a trusted counselor or therapist
- ✓ Seek support from a trusted friend or family member
- ✓ Seek guidance from a trusted pastor, priest, rabbi, or other religious or spiritual figure
- ✓ Seek support from other people who have had experiences similar to yours.
- ✓ Seek out other members of the EASA community
- ✓ Seek books or blogs written by people who have experienced psychosis risk syndrome or psychosis, or self-help books that focus on helping people get through hard times.
- ✓ Keep a journal or blog of your daily feelings so that you can have a safe way to vent your hurts or frustrations.
- ✓ Offer to give the person more information about psychosis.
- ✓ Write a letter to, or have a conversation with, the person about your experiences.
- ✓ Give the person time to think. Disclosure may take others by surprise.





## Messages from EASA graduates

### Advice and experience about disclosure from EASA graduates:

"One, be mindful when disclosing to friends or family. If you have heard them say negative things about disorders that involve psychosis in the past your disclosure may cause tension between you two. However, this could also be a learning experience for them. Just be aware of how the disclosure may impact your personal and emotional safety. When I have disclosed in the past, I've gotten responses ranging from disbelief, fear, and massive support and understanding. Sometimes you never know how people will respond and you should be prepared for that.

Two, at work and school it can be important to disclose your experience if you are requesting accommodations. It can also be helpful in certain situations such as you are working as a peer support specialist or you're in a psychology class where psychosis is being discussed. And three, disclosing to others can be an important part of [relapse] planning, or making sure that future symptoms don't get in the way of your life."

- N., EASA Graduate

"It took me sometime to begin to open up and say, 'I'm bipolar, I've experienced psychosis.' I thought people would judge me, but I was surprised. Most people just want to know more about it. Most people don't really know what psychosis is. The more I discussed it with others, the more people around me became educated and empathetic. Not everyone will receive it well, but most people are willing to listen. Most people are awesome!"

- A., EASA Graduate

"When I had my first manic episode, I thought I was done for. But my dad told me, 'Your diagnosis is just one part of who you are. You are so much more than your label and you are not alone. I'm here for you.' That really went deep and gave me hope."

- EASA Participant

"Disclosure of your symptoms can be a scary experience, and rightfully so. With stigma as it exists today you never know how someone will react. This is almost a catch 22, because talking about these experiences can be most helpful in relieving them. Early on in my 'recovery' I thought that I needed to tell people of my experiences. I would think that if I didn't people would just be able to tell anyway. In navigating my experience of disclosure I've found that it is important to first identify a person that I thought was trust worthy and honest, whether it was in the work place, school or daily life. These were the people I knew would be okay with this information. It is ok to be cautious in who you choose to share these experiences. They are not anyone else's to share for you."

- M., EASA Graduate





...TODAY WE'RE HONORED TO HAVE CARLO WITH US.

CARLO HAS LIVED EXPERIENCE WITH PSYCHOSIS AND HAS GRACIOUSLY AGREED TO SHARE HIS STORY.

**EASART:**  
**CARLO'S COURAGE**



THANKS.

UM, I WROTE A FEW THINGS DOWN...



WHEN THIS BEGAN, I WAS SCARED.

I BELIEVED OTHER PEOPLE COULD HEAR MY THOUGHTS.

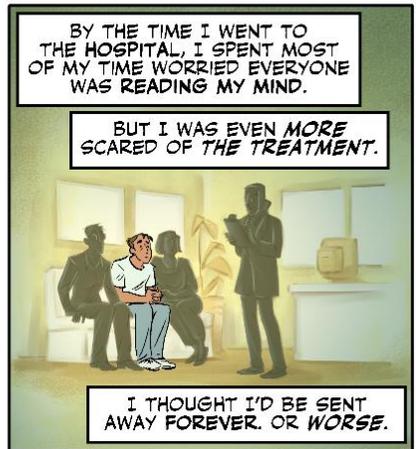
NO ONE LIKES YOU

SEEK THE TRUTH

YOU LOOK STUPID

SOMETHING IS WRONG WITH YOU

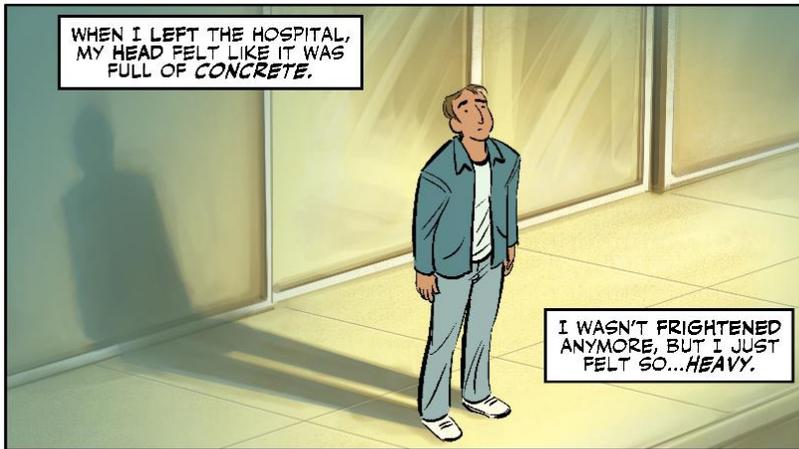
I WAS EMBARRASSED, BUT I COULD KINDA BLOCK IT OUT WITH HEADPHONES.



BY THE TIME I WENT TO THE HOSPITAL, I SPENT MOST OF MY TIME WORRIED EVERYONE WAS READING MY MIND.

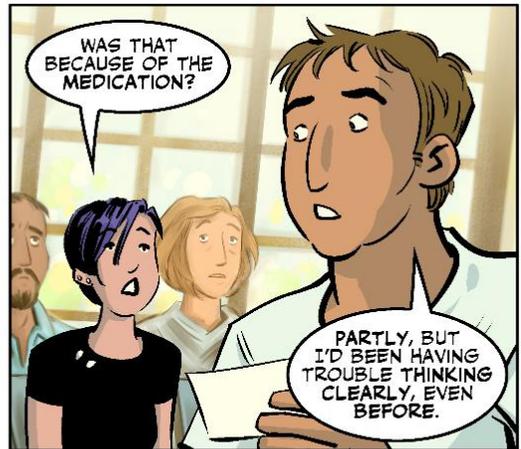
BUT I WAS EVEN MORE SCARED OF THE TREATMENT.

I THOUGHT I'D BE SENT AWAY FOREVER. OR WORSE.



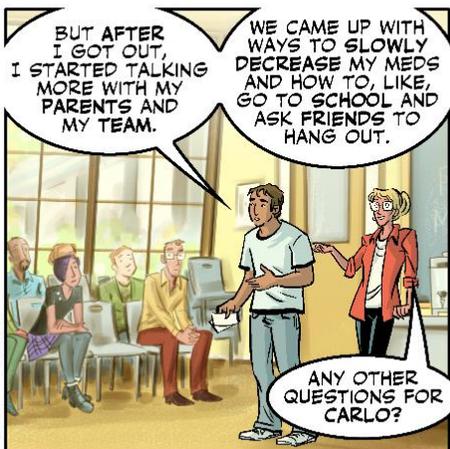
WHEN I LEFT THE HOSPITAL, MY HEAD FELT LIKE IT WAS FULL OF CONCRETE.

I WASN'T FRIGHTENED ANYMORE, BUT I JUST FELT SO...HEAVY.



WAS THAT BECAUSE OF THE MEDICATION?

PARTLY, BUT I'D BEEN HAVING TROUBLE THINKING CLEARLY, EVEN BEFORE.



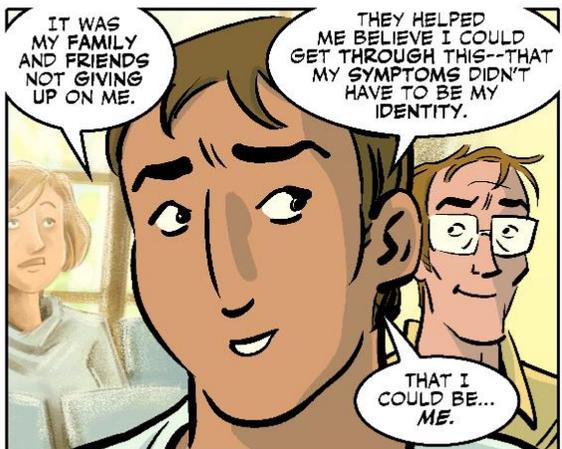
BUT AFTER I GOT OUT, I STARTED TALKING MORE WITH MY PARENTS AND MY TEAM.

WE CAME UP WITH WAYS TO SLOWLY DECREASE MY MEDS AND HOW TO, LIKE, GO TO SCHOOL AND ASK FRIENDS TO HANG OUT.

ANY OTHER QUESTIONS FOR CARLO?



SO, WHAT'S HELPED YOU THE MOST?



IT WAS MY FAMILY AND FRIENDS NOT GIVING UP ON ME.

THEY HELPED ME BELIEVE I COULD GET THROUGH THIS--THAT MY SYMPTOMS DIDN'T HAVE TO BE MY IDENTITY.

THAT I COULD BE... ME.

© 2017 EASA. Character Art by Colleen Coover

## Adolescent and Young Adult Identity

### 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 lifetime<sup>11</sup>.

The meaning a young person gives to their life experiences plays a significant role in how that sense of identity develops and grows<sup>3, 5, 6</sup>. Meanings are "individuals' responses when they reflect on themselves in a role, socially, and personally"<sup>11</sup>. Generally, a young person's sense of identity is about how the person sees themselves, the world, and their place in it<sup>5</sup>.

Identity is informed by the role a person plays in society (like child, student, sibling, actress) what groups the person is a member of (like a sports team, a game club, a faith community, a LGBTQIA community group), and the unique characteristics of each individual. People have different identities at the same time (for example: a teenager, who babysits younger children, plays a sport, is a guitarist volunteers could identify as: babysitter, athlete, and musician). When individuals go through changes in life their sense of identity is affected<sup>4,11</sup>.

### What is happening to my sense of identity as an adolescent or young adult?

Adolescence and young adulthood are life stages when a person's sense of identity undergoes its' most concentrated and rapid growth.

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.

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 when you go through during difficult times can help protect you from the possible negative consequences of those difficult experiences. This might look like going through a hard time and learning more about your sense of purpose in life and get the sense that you grew in ways that are valuable to you from those difficult experiences<sup>4,5</sup>.

Growing your sense of identity involves quite a bit 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<sup>3,5</sup>.



## **What might be different for me and how my identity is growing since I've experienced psychosis risk syndrome or psychosis?**

Great question!

Young people who experience psychosis or psychosis risk syndrome, like their same age peers that do not have these experiences, are developing their sense of identity. That includes having the same kinds of reflections, experiences, and meaning making processes. What is likely different for young people who experience psychosis or psychosis risk syndrome and are developing their sense of identity, is that these young people 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. (For example: having to decide whether or not to start a new job, or pursue someone you are interested in romantically).

Developing psychosis is a significant change in a young person's life and influences their sense of identity and beliefs about who they are as a person<sup>1</sup>. Young people who are developing their sense of identity and experiencing psychosis are probably more vulnerable to having that sense of identity influence by their experience of stigma and social judgment.

Having developed psychosis, you might be more vulnerable to having life experiences and interactions with other people and society that gives you a sense of feeling stuck. That sense of feeling stuck could feel like you are not growing into who you want to become as a person or are not getting them same kinds of positive messages about who you are as a person that you got before experiencing psychosis.

Getting support from people who trust to help you make sense of all your life experiences and of experiences of judgment or stigma can really help you continue to become the person you truly are. Having the support and opportunity to feel validated, understood, and allowed to make sense of psychosis in a way that fits for you, can help you include these experiences in a way that works best for you as a unique individual<sup>3,4</sup>.

## **What can I and other people do to help my developing sense of identity?**

- Learn about typical identity development, for yourself. That way you can separate it on your own and with the right support, what kinds of experiences you are having that is most likely about being a young person and growing up, and what might be more related to having developed psychosis.
  - This can help you identify and manage how you make sense of these experiences and strengthen your perspective.
- Identify people in your life and on your EASA team that asks questions about your life, your hopes and dreams for the future, friends, intimate relationships, spiritual and religious beliefs, worldviews and values.
  - Try to include people who share similarities and differences with in your beliefs, worldviews, thoughts and feelings about life issues. These kinds of conversations and relationships that allow for being similar and different can really help you grow your sense of self!



- Learn about stigma and why it exists.
  - Look at the disclosure hand out and start to decide who in your life and on your EASA team do you sense accepts you for who you. You could think about individuals and groups of people where you feel comfortable, like you are listened to without judgment, and that when you have a sense you are being judged are open to hearing that and making corrections.

### **What can we I do to work protect myself from stigma holding me back in who I am becoming?**

There are probably many ways to do this. Here are some ideas to get you started or add to what you already are doing.

### **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 his or her sense of identity.
- Individuals that 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 (like fear, a sense of protectiveness, anxiety, beliefs about having done something wrong to cause psychosis, guilt) about psychosis 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 (See also Sharing Your Experiences and Information with Others)**

- Stigmatizing messages can be communicated in social interactions like 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, likely send unintended stigmatizing messages to their clients.

### **Problems stigma might create for you**

- Your main developmental ‘job’ during adolescence and young adulthood is to develop your sense of identity.
- In order to develop a sense of identity that is authentic and represents who you truly are, it is important to be involved in life activities that help you learn and grow in your beliefs, worldviews, thoughts, feelings, and across life in general!
- This includes having opportunities to explore their similarities and differences in social relationships and with social institutions that are unlikely or will not judge, based on their different experiences.
- Stigma, if it is not addressed, can lead to a young person who experiences psychosis being left out of the kinds of social opportunities young people who develop psychosis access and participate in that do help them grow.
- These experiences could turn into harmful messages about a person’s worth and identity.

### **How can EASA help me grow my sense of identity?**

- You and someone from your EASA team can discuss ways to identify that another person or group of people will validate who you are and the people or groups of people that will behave in a way that is invalidating.
- From there you can make decisions about your social life and who you want to spend time with.
- Learn about the roots of stigma, and why it exists. Learning about stigma has helped other young people who are vulnerable to getting judged and excluded by other people make some of the experiences less personal. This protects their sense of self so that the bad experiences don’t go inside as far or don’t go in at all<sup>7</sup>.
- Tell people how you want to explain your reason for being in EASA. For example, rather than because I’m psychotic, you might say, I’m hearing voices that get in the way of me doing well in school.
- Allow yourself time to make sense of all the experiences that you have had and continue to have. Giving yourself time and space to do so can help you find ways to fit these life experiences, including psychosis, into your identity in a way that works for you and feels supportive to who you are becoming as a person.



- Give your EASA team honest feedback about your experience of feeling, heard, understood, and accepted. That will help them continue to support you in ways that feel good to you and adjust any approaches that do not feel good to you and are hurtful to your sense of self. For example: Giving a medical provider feedback that when you heard you could not succeed in life without taking medication might have felt limiting or insulting without the provider knowing. Go ahead and let them know, if you feel confident in doing so. That way the provider has a chance to change their message and approach with you.
- Know that you and your family may or may not share the same concerns about stigma. That's okay and can be common<sup>12</sup>. If this creates stress or conflict for you or anyone in your family EASA can help resolve this and get you back on track together.
- Know that being young is on your side! Your sense of identity can continue to grow and change, even throughout and after the most challenging life experiences, including adjusting to the kinds of experiences and challenges that brought you into EASA<sup>3,4,5</sup>.



## What is discrimination and internalized stigma?

"Discrimination" has more than one meaning. The most common meaning is the ability to tell one thing from another; for example, "I can discriminate between the colors blue and orange."

On these pages though, "**discrimination**" is used as its second meaning, which is when someone is treated differently because of some characteristic like their skin color, gender, sexual orientation, religion, or disability. Discrimination can lead to people being treated poorly, being denied opportunities in life, and having their rights taken away. Many kinds of discrimination are illegal, but can be hard to prove.

**Internalized stigma** can happen to people who are discriminated against. It is when someone feels bad about themselves because of the thing people are discriminating against them for. For example, someone with a stutter might start feeling stupid and unloved because they get teased and left out of social events. That feeling of being stupid and unlovable is internalized stigma, not the truth about them.

**Discrimination does not happen because there is something wrong with the person who is being treated badly. It happens for a variety of complex reasons.**



### Why does discrimination happen?

Most people do not want to discriminate against others. They have good intentions, and want to be kind and fair. They discriminate because society has taught them that it's okay, or even necessary, to treat others differently. Often people don't realize they have discriminatory beliefs because their lives are not directly affected by discrimination.

For example, a business owner may have grown up around people who are convinced women aren't as good at math as men because there are less of them working in math-oriented careers. Then when he is hiring a computer programmer, he picks the male applicant instead of the female one because he is worried about his business. Or a provider learns in medical school that people with mental health conditions can't be trusted to make good decisions, so she disregards the wishes of a client with a bipolar diagnosis--even though the decision is a perfectly good one--because she believes it is in the client's best interest.

Sometimes people can be taught to have less discriminatory beliefs and to change their behavior. For example, the business owner might learn that there are less women in math-oriented careers because they have been given less opportunities, not because of their abilities. That might encourage him to hire qualified women and stop discriminating against women.

It's hard to stop discrimination in society because it's so set-in and complicated. However, people do have control over how much they let it get to them. In other words, **we can't always control how someone treats us, but we can control how seriously we take their behavior.**





## How do I know if I'm experiencing discrimination because of psychosis risk syndrome or psychosis?

Discrimination can be obvious, like being told, "We won't hire you because we don't hire people with a history of psychosis." But it can also be subtle, like having people move further away from you when they learn you have experienced psychosis risk syndrome or psychosis. Unfortunately, there is no easy rule for knowing if something is discrimination or just someone in a bad mood unless it's obvious like in the first example.

One thing that might help is to consider if the person acts the same way with people who have not experienced psychosis—if not, it might be discrimination. Another thing that might help is to ask a trusted person for their opinion—if more than one person is perceiving the same thing, it is more likely true. A third thing you can do, if you feel safe and comfortable doing so, is to ask the person themselves if it's discrimination.

Sometimes people don't realize that they are being discriminatory. A casual way to ask, if you otherwise trust the person, might be, "That made me feel weird, like you only did it because I've experienced psychosis. Did you mean it that way?"



## Talking about discrimination with family and friends

Fear of discrimination sometimes makes it harder for people to talk about their experiences of psychosis, even with family and friends who love them. It's important to talk to family and friends about discrimination and internalized stigma. Sharing can help reduce stress and fear around these topics. It can help others understand you better, and learn how to become more aware of how they might discriminate without realizing it.

Here are some tips for bringing up the topic with family and friends.

- ✓ **Plan and practice what you want to communicate.** You may want to write down your thoughts and feelings to help organize them.
- ✓ **Choose the people who you know will be the most understanding,** or you find easiest to communicate with, first.
- ✓ **Choose a time to talk when the person has time and energy for a conversation.**
- ✓ As much as is possible, **be polite, calm, and speak from your own authority.** Family and friends have good intentions, even when they have not learned how to express those intentions well.
- ✓ **Be prepared for a range of responses.** Some people might respond well, others poorly. Some people might need extra time to work through their own feelings about discrimination.



## Teaching providers to be sensitive to discrimination

Like the other people in your life, providers usually don't want to be discriminatory but do not always recognize when they are. Some providers were trained in programs that had



discriminatory attitudes, and they haven't broken out of that mind set all the way. Some can get defensive about their beliefs. This might put you in the situation of having to teach them.

Here are three tips that might be helpful.

- ✓ **Let your provider know when something they've said or done has made you feel bad or like you're being treated differently.** For example, "When you tell me I don't need to know important information about my medication, or you dumb down the information, it makes me feel disrespected."
- ✓ **Come up with non-discriminatory alternatives,** if you can. For example, "You can give me the same information you would give anyone else about the medication. I'll let you know if I don't understand it."
- ✓ As much as is possible, **be polite, calm, and speak from your own authority.** Think of yourself as the expert on your experience.



### Quick tips to protect against internalized stigma

It's hard to experience discrimination and not have it effect you negatively. Here are three things to keep in mind to help protect against letting other people's discriminating attitudes get to you.

- ✓ **You are not responsible for other people's prejudices.** Other people's prejudices are their own responsibility to figure out and deal with.
- ✓ **You are not your medical labels or diagnosis.** You are a human being, and how you define yourself—including how you accept or reject any medical labels—is our choice.
- ✓ **You deserve to be treated with respect.** When others treat you poorly, it is not because you deserve it.





## Messages from EASA graduates: Self-Acceptance and Healing

**P:** EASA is a safe place to be yourself without judgement and stigma from others.

**M:** The more you're open about your diagnosis or experiences, the easier it gets.

**NB:** Self-acceptance can lead to embracing the label of schizophrenia and wearing it openly. Being comfortable with it, as part of one's self, can help other people be less afraid of it. Self-acceptance and openness can lead to changes in social acceptance. It's not so much of a frightening experience anymore.

**A:** Having the courage to blossom out and rediscover yourself is really important.

**M:** For me, overcoming challenges with mental illnesses wasn't something I wanted to share with just anyone. In fact, when I first started EASA most people thought I was back at school. EASA helped me decide how I wanted to tell my story. At first, I was afraid people would judge me, but I realized people were thrilled to see me. Sometimes it's hard being diagnosed with psychosis and bipolar but my life is fuller and richer because of it, and I'm happy with the person I am. I wouldn't have it any other way.

**P:** Self-judgement doesn't help with recovery or goals but confidence and acceptance allows for progress. People can do a wrong thing without it meaning that they are wrong.

**NB:** Even if what you did was criminally wrong, it's forgivable. You're not a criminal. What you did in the past might be wrong but that doesn't make you a bad person. Past mistakes don't define who you are.



## Tools for Treatment and Recovery

### **A Guide for Using the Self-Advocacy Toolkit**

This toolkit includes strategies that you may find helpful to use to assist you in focusing on what is important to you and communicate your needs to your EASA team, family members, and/or supporters. It was developed as a collaboration between Mary Bryant and members of the Young Adult Leadership Council (YALC), with support from Pat Deegan [http://www.easacommunity.org/PDF/Self-Advocacy-Toolkit\\_Young-Adult-Guidance\\_2.15.17.pdf](http://www.easacommunity.org/PDF/Self-Advocacy-Toolkit_Young-Adult-Guidance_2.15.17.pdf).

### **When would I use these tools?**

Use Tool # 1 “This is Who I Am” to introduce yourself to members of your treatment team. This tool may help you articulate what you typically experience and what a rough day looks like for you, what is important to you, your strengths, and areas where you would like to grow or improve.

[http://www.easacommunity.org/PDF/Self-AdvocacyTool\\_1\\_2.8.17.pdf](http://www.easacommunity.org/PDF/Self-AdvocacyTool_1_2.8.17.pdf)

Use Tool #2 “Communicating with My Team” to clarify what you want or do not want from treatment and to plan what to discuss in meeting with your treatment providers.

[http://www.easacommunity.org/PDF/Self-AdvocacyTool\\_2\\_2.8.17.pdf](http://www.easacommunity.org/PDF/Self-AdvocacyTool_2_2.8.17.pdf)

Use Tool #3 “What Helps Me Find Calm and Safety” to share what you think will help or not help you manage stress and stay well.

[http://www.easacommunity.org/PDF/Self-AdvocacyTool\\_3\\_2.8.17.pdf](http://www.easacommunity.org/PDF/Self-AdvocacyTool_3_2.8.17.pdf)

### **How do I decide what to share with my treatment team?**

Sharing personal information with new people is a process for most of us! People’s comfort level with disclosing personal experiences, thoughts, feelings, beliefs, and worldviews often change over time.

Spending time with another person can help build a sense of trust and safety so you can make decisions about what you do and do not feel comfortable sharing with others. That is okay, and quite normal!

Hopefully with ongoing contact and reflection about what you want to share with others, you will be able to make decisions about what to share about your goals and concerns with your support network and treatment team.



## Relapse Prevention Planning

**Relapse prevention planning is a way to prevent psychosis risk syndrome or psychosis from getting in the way of your goals, once you have started getting back to your life (See Appendix D for a copy of a relapse prevention plan).** Relapse prevention planning involves identifying the triggers that can cause a relapse, 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 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 you achieve your dreams and goals;
2. a set of things you can do on a regular basis to prevent a relapse;
3. a tool to help communicate with others about what you need, and what they can do for you.

Your EASA team, along with your family members and friends, will work with you to create a relapse prevention plan to identify the triggers that can cause a relapse, the early warning signs that are unique to you, 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 that you need included in it.



## Taking Care of Yourself



People may find it hard to take care of themselves when they are not feeling well. But taking care of one's self can also be what helps people feel better. There are some small, easy things that might be useful to you to help you feel a little better, even when you're not feeling well. They include strategies for stress-relief, improving health and wellness, and dealing with unpleasant or unwanted symptoms.



### Stress-relieving Strategies

**Mindfulness** - Being mindful means taking time to be aware of what is happening in the world around you and in your own thoughts without judging them. It means being in the present moment and not dwelling on the past or worrying about the future, but concentrating only on what is happening right now, in the moment. For example, sitting in the yard and feeling each breath in your lungs, feeling the breeze on your face, paying attention to the damp, grassy smell and the sound of the birds and the pulse of your heart, and being fully aware and present in that moment. You can find out more about mindfulness techniques at the Berkeley Greater Good Science Center.

(<https://greatergood.berkeley.edu/topic/mindfulness/definition>)

**Meditation** - Mindfulness is one kind of meditation. There are many other kinds of meditation practice, like breathing focus, yoga, mantras (repeated words or phrases), and mandalas (images to focus on). For example, a meditation practice might be to sit in a particular position and count your breaths. Some meditation may be easier to learn than others, and they generally become more effective the longer you practice them. You can find some guided meditations at the UCLA Mindful Awareness Research Center.

([https://www.uclahealth.org/marc/body.cfm?id=22&iirf\\_redirect=1](https://www.uclahealth.org/marc/body.cfm?id=22&iirf_redirect=1))

**Ordinary things daily life that make you feel good** can help relieve stress too. Examples are hanging out with pets, going for walks or runs, taking hot baths or showers, coloring or making art, listening to favorite music, watching favorite movies, or anything that makes you feel relaxed and good about yourself.



### Health and Wellness Strategies

**Sleep** - One of the most important things that you can do to feel better is get the right amount of sleep. Sleep is the time when your mind and body repair themselves. You can learn more about the importance of sleep from the National Institute of Health (<https://www.nhlbi.nih.gov/health-topics/sleep-deprivation-and-deficiency>).

If you are having trouble with sleeping too much or not enough, talk to your EASA team members about ways to improve sleep.



**Nutrition** - Eating well helps people feel well. If you are not eating enough or are eating too much, or if you cannot figure out how to eat healthy, talk with your EASA team to strategize about ways to eat more nutritiously.

**Physical Activity**- Being physically active is as good for the mind as it is for the body. Scientific studies have even shown that exercise can help stop depression. The most important step is finding a physical activity that you like doing. That could be dancing to your favorite songs, taking your dog for a walk, or playing basketball with a friend. Ask your EASA team members to meet you at the park or go for a walk with you in your neighborhood.

**Recreation** - Having fun isn't just goofing off--it improves moods and health. If there is something you like doing that you find easy to do, do it! Making art, hiking, watching movies, playing games--whatever it is you enjoy most can help you feel better.

There a lot of online resources about health, exercise, and recreation. Ask your EASA nurse or other EASA team members to help you find additional resources and supports.



### Symptom-related Strategies

If you hear voices, see visions, or have tactile (touch) sensations that are giving you trouble, here are some quick things that can help:

- ✓ **If you notice a warning sign beforehand, try relaxation or breathing to try to stop them from fully forming.**
- ✓ **Don't believe what negative voices, visions, or sensations tell you.** Nothing says you have to believe them, act on what they say, or that they are right. Your actions are your choice, not theirs. Nothing says you have to see something bad in a vision. There are many different interpretations of visions.
- ✓ **Keep busy, practice hobbies, listen to music, engage in an activity you enjoy that will be louder than the visions, voices, or sensations.**
- ✓ **Make up rules for how you will engage with the voices, visions, or sensations and stick to it.** For example, let them know they can only speak to you after ten at night and don't let them try to talk you into any sooner.

It is OK to talk about voices, visions, or other unusual experiences in EASA groups. There is a good chance someone else in the group has had a similar experience, and you can help each other out.

Click the link to find a longer list of things you can do from the Manchester Hearing Voices Group: ([http://www.hearing-voices.org/wp-content/uploads/2012/05/Hearing\\_Voices\\_Coping\\_Strategies\\_web.pdf](http://www.hearing-voices.org/wp-content/uploads/2012/05/Hearing_Voices_Coping_Strategies_web.pdf))





### Compassion for Voices

Ask your EASA team members about this approach. It may be helpful to you if you hear voices. The link <http://compassionforvoices.com/> has a lot of resources, as well as a 5 minute video that you can watch to learn more.



### Radical Acceptance

Radical acceptance is a way of **looking at the bad things that happen and letting them just be bad and moving on**, rather than fighting against them or trying to fix them. It does not mean people shouldn't try to improve the things they *can* change. It means that sometimes people are happier or better off accepting the things they *can't* change and getting on with life.

Imagine you made big plans to go hiking. When you wake up, it's raining, and your friend who was going to drive does not want to go. You could deny the weather and the lack of transportation, and hitch hike and slog it alone in the rain anyway no matter how miserable it makes you. You could spend the rest of the week angry and dwelling on the missed opportunity. Or instead you decide to look at what happened through the lens of radical acceptance. You let yourself be disappointed and angry, realize the weather is beyond your control, honor the loss of the hiking—and then consider what else might be fun to do with your day. This is an easy example of radical acceptance, but the same idea can apply to much more painful, unfair things in life, including symptoms.



### Time Heals

When people feel bad it can seem like life is over and things will never get better. But life is always changing, and bad times will change to better times, eventually. A lot can happen in even just two years.

Trust in the process of learning, growing, and participating in the EASA program. You may not end up where you expected to, but doesn't mean you won't end up in a place where you want to be.

*“I coordinate the EASA program all around the state of Oregon and I've been doing that since 2001. When people first start coming into our program quite often things are harder than they used to be and it's easy to get discouraged and lose confidence. And the important thing to know is that there is a way through that, and that a good place to start is with something that you love whether it's riding your bicycle or playing the guitar or watching videos that make you laugh, there's really no wrong place to start, just stay focused on the things that you love and your confidence will come back, and there is a way through it.”*

—Tamara Sale, Director, EASA Center for Excellence



# SECTION 3: TRANSITION



## Pathway Towards EASA Graduation



EASA is a transitional program that focuses on early intervention. However, even after your time in EASA 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 you graduate from EASA. With your permission, EASA programs throughout the state may reach out to you and your family members or friends to ask you to come speak about your experiences in EASA to other families, young people, or people in the community.

EASA services focus on supporting a grounded and positive view of the future. The EASA team in partnership with the you, your family members, and other supports, anticipates what the time period at and after completion of EASA will look like.

Your EASA team will be talking with you about transition out of services from the beginning of your time in the program to prepare. A formal **transition plan (See Appendix E)** will be completed at least 6 months prior to your transition from EASA, and will include you, the EASA team, and your family members and other supports. Your transition from EASA into other services and/or supports is a gradual process. It is important to let your EASA team members know how transition is going for you and your family members and supporters, and to have your EASA team members help you problem-solve any challenges or barriers that may be coming up.



## EASA Transition Checklist

EASA teams use a transition checklist to help ensure that all areas of need are addressed before you graduate from EASA, or to ensure that there is a plan to address needs that have not been met with other services outside of EASA. The transition checklist should be filled out with you, your EASA team members, and your family members and other supports. Transition planning is an important part of EASA and should include everyone who is involved in your treatment. See **Appendix E** for a copy of the checklist.

The Transition Checklist includes the following:

- ✓ **Wellness Plan/Relapse Prevention Plan:**
  - Information regarding your strengths
  - Information regarding your 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 you and your 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
  - You have 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 you to access transportation to appointments
  
- ✓ **Counseling/Therapy:**
  - You plan to continue receiving counseling services and, if so, have identified and met your 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 you are currently prescribed medication, there is a plan in place for accessing medications, including identifying a prescriber you will see
- A plan has been established to access and pay for medication for the next 3 months

✓ **Treatment Goals:**

- You have completed treatment goals or have a clear path to completing them (including housing, educational, and/or vocational goals)
- All goals have been reviewed with the you, your 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 you are ready for transition
- A transition meeting has occurred with you, your 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.
- Young people 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



Your time in the EASA program is honored 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 you, your family members, and friends to honor this important transition in a meaningful way.

My 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 you and your 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 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 you graduate 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 supports giving people the information they need to be effective self-advocates at individual, agency and system levels by:

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

After graduation, you will continue with your new providers, as well as be invited to return to participate in EASA events, planning, and development activities. If you are interested, ask your EASA team members how you can be a part of these activities.

### Staying Connected to EASA After Graduation

There are many ways to stay connected with EASA after the 2 years end. In addition to being invited back to share your experiences or participate at 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. Talk with your EASA team about ways for you to stay connected to your local EASA program or to the statewide EASA efforts.

### Additional Resources and Support from EASA After Graduation

Although you 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 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:




---



## Connections to Additional Supports

### **EASA 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 is a great opportunity! On the Young Adult Leadership Council, you get to work with peers on creative projects. It allows you to begin networking with other advisory groups and get involved with what you are interested in. YALC participants receive an hourly stipend and travel reimbursements for meetings and events. As a member of the Council you 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. We encourage you to join and share what you have to offer!

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

Visit [www.easacommunity.org](http://www.easacommunity.org) for more information. You can visit [http://www.easacommunity.org/PDF/EASA\\_YALC\\_Application\\_2019.pdf](http://www.easacommunity.org/PDF/EASA_YALC_Application_2019.pdf) to download the application or ask an EASA team member for a paper application. Please [eesa@ohsu.edu](mailto:eesa@ohsu.edu) if you need additional assistance.



## **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.

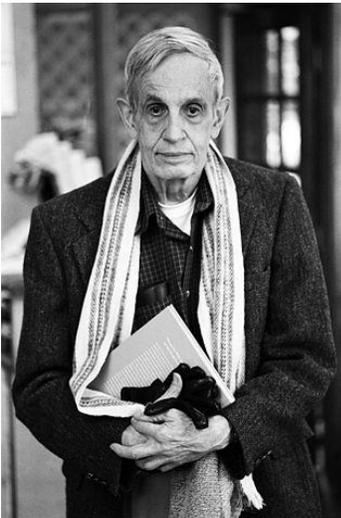
Family and friends of EASA participants can visit the FFLC page on the EASA website [www.easacommunity.org/fflc.php](http://www.easacommunity.org/fflc.php) to get more information, apply for a position on the Council, and to subscribe to the email group. They may fill out the FFLC application [http://www.easacommunity.org/PDF/Fillable EASA FFLC Interest Form 2018-edit-11.29.18.pdf](http://www.easacommunity.org/PDF/Fillable%20EASA%20FFLC%20Interest%20Form%202018-edit-11.29.18.pdf) and email it or mail a hard copy to the addresses listed on the application. They can also email [easa@ohsu.edu](mailto:easa@ohsu.edu) for additional assistance.



## Success is How You Define It

Can a person who experiences psychosis risk syndrome or psychosis be successful?

Absolutely! In fact, some people who have these experiences may have been successful because they see things differently. Here are some individuals who have shared their experiences with psychosis:



John Nash was a mathematician who won a Nobel Prize.

His mathematical work has helped people to understand economics, artificial intelligence, and politics, among other things.

John Nash is the subject of the book and movie "A Beautiful Mind." Nash managed his psychosis by using his mathematical, rational thinking to sort out what was real and what was not.

Photo by Peter Badge / Typos1  
- OTRS submission by way of  
Jimmy Wales, CC BY-SA 3.0  
<https://commons.wikimedia.org/w/index.php?curid=6977799>

Elyn Saks is a Professor of Law, Psychology, and Psychiatry and the Behavioral Sciences.

She is an expert on mental health law and has won distinguished awards for her work, including a MacArthur "genius" award.

Elyn Saks wrote a best-selling memoir called *The Center Cannot Hold*. She manages her psychosis with medication, therapy, and a supportive environment. You can watch her give a [TED talk](#) on YouTube.



"ELYN SAKS 9" by Courtesy of the John D. and Catherine T. MacArthur Foundation.  
Licensed under CC BY 4.0 via Commons



Brian Wilson is a musician and music producer who was inducted into the Rock & Roll Hall of Fame in 1988, and who has won two Grammy awards.

He was one of the founding members of the Beach Boys.

Brian Wilson's life is the subject of the movie "Love & Mercy." He manages his auditory hallucinations with therapy and the support of his wife.

"Brian Wilson 2009" by wonker - <http://www.flickr.com/photos/wonker/3885099919/>.  
Licensed under CC BY 2.0 via Commons  
[https://commons.wikimedia.org/wiki/File:Brian\\_Wilson\\_2009.png#/media/File:Brian\\_Wilson\\_2009.png](https://commons.wikimedia.org/wiki/File:Brian_Wilson_2009.png#/media/File:Brian_Wilson_2009.png)



Kay Jamison is a clinical psychologist and writer. She is a professor at John Hopkins University.

Time Magazine called her a "hero of medicine," and she also received a MacArthur "genius" award.

Kay Jamison's wrote a memoir *An Unquiet Mind* about her experiences with psychosis and bipolar disorder. She manages her psychosis with medication, therapy, and support from others.

"JAMISON754" by Unknown, Copyright Holder is JHMI - Received from Eric Vohr, Media Relations, Johns Hopkins Medical Institutions. Licensed under CC BY 2.5 via Commons - <https://commons.wikimedia.org/wiki/File:JAMISON754.JPG#/media/File:JAMISON754.JPG>

Wesley Willis was a musician and visual artist.

He is famous for his drawings of the Chicago streets, and for his punk band the Wesley Willis Fiasco, which produced nearly 50 records in ten years, and appeared on MTV.

There are two documentaries about Wesley Willis, *Wesley Willis: The Daddy of Rock 'N' Roll* and *Wesley Willis's Joyrides*. There are also numerous videos of him on YouTube, including this one that shows him [making his art](#). He used his different way of thinking and perceiving the world to create his unique art.



## Your Fellow EASA Graduates



There is no need to win awards, have huge goals to save the world, or have a book or a movie about you to be successful. The EASA graduates who have been sharing their stories with you have all succeeded in their own goals to finish school, to get their own place, make art, or to take steps in whatever direction their dreams for the future lie.

“Remember, there was a time before psychosis and there will be a time after too. Your life will normalize again. This, too, shall pass.”

- P., EASA Graduate

“Who you become is rooted in who you are and where you started. Success grows from your natural strengths, talents, skills, and passions.”

- M., EASA Graduate

“The experience of psychosis can add to or enrich your life, clarify your goals, help you to see what really matters to you in life, and better define and direct your own success.”

- A., EASA Graduate



## 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](http://www.easacommunity.org)), there are many other places to find additional resources and information to support you in your recovery. 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 know if you need any of these materials or resources in languages other than English or another format for you, family members, or other supporters.

Here are some additional resources to explore with your EASA team members, family members, or on your own. There are many resources available that focus on recovery and provide information about individual's lived experience with psychosis.

The Here to Help project in British Columbia has a downloadable online toolkit for youth experiencing psychosis.

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

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

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



Appendix A: EASA Strengths Assessment

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?
<b>Daily Living Situation</b>		
<b>Financial/Insurance</b>		
<b>Vocational/Educational</b>		
<b>Social Supports</b>		
<b>Health</b>		





## 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 \_\_\_\_\_

MH Prescriber \_\_\_\_\_

Phone \_\_\_\_\_

Primary Care Physician \_\_\_\_\_

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



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

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



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

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



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

Evaluate identified risk items and develop crisis plan accordingly.



## Appendix D: Relapse Prevention Plan

<b><i>Relapse Prevention Plan</i></b>
Reminder of events or situations that triggered relapses in the past: 1. 2. 3. 4.
Reminder of early warning signs that I experienced in the past: 1. 2. 3. 4.
What I think would help me if I am experiencing an early warning sign: 1. 2. 3. 4.
Who I would like to assist me, and what I would like them to do: 1. 2. 3. 4.
Who would I like to be contacted in case of an emergency? 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 refer-  
rals:  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 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 4<sup>th</sup> 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 \_\_\_\_\_





## Appendix G: 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

<b>Is your loved one:</b>		
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: _____

<b>Is there any assistance that will help you to participate?</b>
_____
<b>Would you be able to make a 6-12 month commitment?</b> <input type="checkbox"/> 6 month <input type="checkbox"/> 12 month
<b>Do you speak any language(s) other than English?</b> _____
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





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