The EASA Young Adult Leadership Council is the outgrowth of Oregon’s Early Assessment and Support Alliance, the first statewide effort to make early psychosis intervention universally available in the United States. Our group, which was created in April 2013, consists entirely of young adults who have graduated from EASA, as well as representatives from Youth Move. The Leadership Council works to unite the voices and strengths of young adults and their allies in order to help create a thriving community and a revolution of hope. Having directly experienced psychosis, we deeply appreciate how profoundly important these programs are. In reflecting on our experiences and the great momentum toward early psychosis intervention, our group has made the following recommendations for national policy development:

✓ The EASA Young Adult Leadership Council is interested in any attempts currently going on to reduce negative attitudes and discrimination. We look to our national partners to provide an encouraging message to people new to these conditions by eliminating the use of descriptions of schizophrenia such as “chronic, severe, and disabling” or bipolar disorder as “degenerative” which may be the first words a young person reads when they start to research their condition. We hope to replace this language with accurate but hopeful words which emphasize the real likelihood of improvement with the right treatment and support.

✓ We look forward to the day where there are bodies such as the EASA Young Adult Leadership Council nationally and in every state of the country, linked to each other and to national policy efforts.

✓ As programs are created throughout the country, we advocate that every early psychosis program should integrate people with lived experience of psychosis, particularly young adults, into decision making at all levels.

✓ We observe large discrepancies across communities and states in the services available for teenagers and young adults experiencing psychosis. Quality care for psychosis is essential regardless of public or private insurance and no matter where we live.

✓ It has been our experience that peer support is a critical component of our recovery and is not replaceable by any other professional discipline. Individuals who have lived with psychosis bring a level of deep knowledge and grounded hopefulness which is extremely powerful for others and extremely informative for the evidence base.
We should not wait for individuals to be hospitalized or arrested before they can access care. We need proactive education about the early signs of psychosis for psychiatrists, other medical providers, schools and others.

Many of us have been arrested and had to deal with the long-term ramifications of criminalizing mental illness. Coping with legal charges or even “not guilty by reason of insanity” on our records creates a significant stressor and subjects us to long-term discrimination in housing, employment and other aspects of our lives. Psychosis should not be criminalized. Our communities need rapid early access to effective care, police training, diversion programs to keep people out of jail and the court system, and strong protections against rampant discrimination in employment, educational institutions and housing.

Education of psychiatrists and other medical providers should better reflect shared decision making processes and feedback from people receiving their care. Common early signs, side effects (including antidepressants triggering mania), sleep issues, and potential alternatives to medicine should all be part of the educational process.

Discriminatory and dehumanizing practices in hospital and other mental health care settings must be discarded. Being hospitalized should not mean that we lose our right to fresh air, privacy, and informed consent.

In outpatient care as well as inpatient, we need to continue to work toward giving service recipients more agency in the care they receive. Restrictive practices in mental health services which do not exist in the “physical health” world need to be challenged. Examples include requiring clinician approval to access one’s own mental health records, or being denied the ability to talk to a psychiatrist directly about side effects or other medical concerns.

As marijuana becomes more readily available nationally it will be important to educate the public about the potential for marijuana to trigger psychotic symptoms in those who are vulnerable. Additional research about the impact of marijuana on psychosis is needed. Education should not be fear-based, but informative.

Housing and employment are intertwined on the road to independence; we see a need for stronger emphasis on looking for and maintaining employment as well as a structured path to independent living. Additional access to supported employment resources as well as time limited housing assistance can support us in becoming independent members of society, rather than dependent upon government money. We want to pursue our occupational dreams and goals and contribute our talents to society. We just need a little more help.