# Society for Transplant Social Workers
# Mission Statement

*Make a difference in the lives of our patients and their families.*
*Connect with and motivate each other.*
*Promote professional growth.*
*Collaborate to advance social work in our field.*

The Society of Transplant Social Workers (STSW) was founded in 1985 with the goal of supporting social workers in transplant settings, networking, and establishing best practices in a highly complex healthcare setting.

We appreciate the work of the OPTN Ethics Committee in reviewing the General Considerations in Assessment for Transplant Candidacy which focuses on the non-medical criteria used in determining transplant candidacy by the multidisciplinary team. We agree with the goals set out by the Ethics Committee to balance the ethical principles of autonomy, justice and utility for the individual person being considered, donor families, and transplant programs as well as for the larger society all the while considering the "first do no harm" axiom. Racial and ethnic disparities in transplantation are well documented and must be mitigated by the work of the patient, community and the multidisciplinary transplant team to ensure a good outcome after transplant. Poor outcomes are not just negative numbers on a spreadsheet; they reflect morbidity and mortality for transplant recipients.

There is variability on whether a person is considered a transplant candidate based on criteria, medical and non-medical, across transplant centers. Transplant candidacy criteria should be transparent and equally applied within the transplant program itself. Transplant candidates should understand the importance of getting a second opinion if found to not be a candidate at one center, whether for medical or non-medical reasons.

STSW appreciates the opportunity to add our comments to this work.

- *Transplant centers are encouraged to develop their own guidelines for transplant consideration. Each potential transplant candidate should be examined individually and any and all guidelines should be applied without any type of ethnicity bias.* (lines 65-67)
    - We would support broadening the attention to bias in its many facets.
- *Life Expectancy… Age does not offer the full picture in determining the life expectancy and it precludes the possibility of some individuals being listed who might otherwise have made good candidates, thereby not respecting their autonomy.* (lines 108, 120-122)
    - While this guideline is not uniquely in the purview of transplant social workers and the 1 and 3 year graft and patient statistics are important and mandated, perhaps from a patient autonomy perspective the calculation could also be focused on longevity with transplant in comparison to medical management of the end organ failure.
    - We support that age in and of itself should not serve as a sole criterion.

- *Potentially Injurious Behavior…Ethical concerns persist with using potentially injurious behaviors (e.g. substance abuse, unhealthy eating, non-adherence to medical recommendations, etc.) as criteria to rule out transplant candidacy.*(lines 124-126)
    - Understanding a person's actions contextually is a critical part of comprehensive assessments by all members of the multidisciplinary healthcare team. For patient safety, along the transplant continuum, many matters are important to optimize prior to transplant such as reducing risk of substance use relapse, improving mental health and optimizing nutritional health.
    - Additional research should be done to better identify factors that are predictive of a person participating in potentially injurious behavior post-transplant and what interventions are most likely to reduce that risk.
- *Adherence… Adhering to a medical regimen post-transplant increases the likelihood of a successful transplant, increasing utility. Thus, transplanting patients who will be adherent is supported by the principle of utility.* (lines 158, 161-162)
    - We agree that not only does adherence to the complex post-transplant regimen increase the utility of the transplant; it also is intended to promote patient safety.
    - Additional research does need to be done to identify reliable, objective measures of adherence to medical recommendations, what factors are most predictive of post-transplant adherence to medical recommendations and what interventions are most likely to reduce the risk that they can pose.
- *Immigration Status… While immigration status may be tightly intertwined with other psychosocial and financial factors that affect a person's candidacy for transplantation immigration status alone should neither determine nor exclude a person's candidacy for organ transplantation as these would be unduly compromise justice 203 and respect for persons.* (lines 196, 200-203)
    - Access to resources needed to manage a transplanted organ is one of the many factors taken into account when considering transplant candidacy. In our current healthcare system, there are fewer resources for undocumented immigrants which can make post-transplant management more complex.
    - Perhaps UNOS should consider removing immigration status from the database questions when listing a person for transplant.
    - An opportunity for advocacy exists to expand health care resources to include people who are undocumented.
- *Social Support… Transplant teams using social support criteria commonly require a potential transplant candidate to demonstrate existing social support to assist with the wide range of post-transplant requirements, such as transportation, medication management, and monitoring symptoms.* (lines 219, 222-224)
    - We agree that the term "social support" is broad, defined in literature in a variety of ways and defined differently by various transplant centers.
    - Comprehensive assessments include assessing whether a person and/or their support system can manage complex post-transplant care needs for the patient's safety in the short and long terms.
    - Additional research would be beneficial to identify which factors are most predictive of post-transplant challenges that could negatively impact success after transplant and what interventions are most likely to reduce the risk that they may pose.

- An advocacy opportunity exists to develop additional community supports to address some of the unmet needs patients sometimes find.
- KDIGO highlights that while there is little evidence that "absence of social support is an absolute contraindication to transplantation. However, in light of the complexities of progressive kidney failure, its treatment, and the associated demands of post-transplant recovery and rehabilitation, we recommend that patients who are unable to engage independently in self-care activities have an identified support system in place prior to transplantation." Virtually all people will experience some postoperative recovery needs.

We are committed to our National Association of Social Workers Code of Ethics aligns with the OPTN Guidelines imperative of applying listing criteria without bias:

> Social workers should not practice, condone, facilitate, or collaborate with any form of discrimination on the basis of race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, or mental or physical ability.

The comprehensive psychosocial assessment is intended to identify a potential candidate's strengths and areas that need to be addressed prior to successful transplant. Potential candidates may be asked to optimize certain factors as a result of the assessment with accompanying resources, when available, being offered. Transplanting people who do not have the necessary pieces in place, puts them at risk for serious complications after transplant up to and including graft failure and death. Balancing autonomy, justice, utility and safety are critical for the transplant community to hold as a high standard across all disciplines and all evaluation criteria.

The Society for Transplant Social Workers strongly supports research efforts to identify which non-medical factors are most predictive of post-transplant challenges that could negatively impact success after transplant and what interventions are most likely to reduce the risk that they may pose. We would be happy to participate in conversations related to that effort.

There are many factors in the transplant realm that are hard to quantify, apply uniformly across transplant programs and it is difficult to do prospective studies from medical and ethical perspectives. In 2018 we participated in consensus building work with the International Society for Heart and Lung Transplantation (ISHLT) around the psychosocial evaluation of adult cardiothoracic transplant and long-term mechanical support candidates. Some of the literature that we rely on, as transplant and mechanical support social workers, when developing best practices, include the following:

- KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation, Revised January 6, 2020. Steven J. Chadban, BMed, PhD, et al.
- The Stanford Integrated Psychosocial Assessment for Transplant is Associated with Outcomes Before and After Liver Transplantation, December 15, 2020. Sasha Deutsch-Link, MD, et al.

- The 2018 ISHLT/APM/AST/ICCAC/STSW Recommendations for the Psychosocial Evaluation of Adult Cardiothoracic Transplant Candidates and Candidates for Long-Term Mechanical Circulatory Support. July 1, 2018. Mary Amanda Dew, PhD, et al
- Why It is Important to Consider Social Support When Assessing Organ Transplant Candidates? October 24, 2019. Jose R. Maldonado, MD

Thank you for the opportunity to share our thoughts on this important work. We look forward to working together in the future.