A Change Package To Increase Kidney Transplantation

Key Change Ideas for Dialysis Facilities to Drive Local Action

ESRD NCC
NATIONAL COORDINATING CENTER

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I. Introduction

This change package is intended to support dialysis facilities and End State Renal Disease (ESRD) Networks in increasing the number of patients referred to transplant centers, evaluated for kidney transplantation, and placed on transplant waitlists. The change package includes actionable change ideas, collected from top-performing dialysis facilities related to patients' being placed on transplant waitlists. The change ideas are intended as a menu of interventions from which leaders can choose to implement within their facilities.

Improving Kidney Transplantation Matters

More than 37 million people in the United States have kidney disease, which was the ninth leading cause of death in 2017 and is estimated to cost $114 billion each year.[1,2,3] Most Americans with ESRD start treatment on dialysis, which can be burdensome and draining on patients and their caregivers. In addition, one in five people will die within one year of starting dialysis.[3] Kidney transplantation, on the other hand, is generally associated with better outcomes when compared with dialysis.[4] Unfortunately, only 30 percent of people with kidney failure are living with a functioning transplant.[5] That percentage could improve by increasing the number of patients on transplant waitlists in concert with other transplantation and organ donation efforts.

A Nationwide Effort to Improve Kidney Care

In 2019, the U.S. Department of Health and Human Services launched the Advancing American Kidney Health Initiative, which outlines several bold goals to address kidney disease issues in the United States.[6] The initiative focuses on fewer patients developing kidney failure, fewer Americans receiving dialysis in dialysis clinics, and more kidneys being made available for transplant. Regarding kidney transplantation, the initiative has set a goal of 80 percent of patients newly diagnosed with ESRD receiving dialysis in the home or receiving a transplant by 2025. Dialysis facilities play a central role in achieving this goal. This change package was developed to support facilities in their efforts to give patients with ESRD the opportunity to get on kidney transplant waitlists, which could lead to successful transplantation.

How to Get Started

Change happens at the local level. Dialysis facility Quality Assessment & Performance Improvement (QAPI) meetings are the perfect place to start. Giving interdisciplinary team (IDT) members this change package for review will allow them to identify and prioritize change ideas that could be implemented to increase the number of patients educated, referred to a transplant center, and waitlisted for a kidney transplant.

The change ideas presented in this change package represent the practices used by high-performing dialysis facilities. They are not meant to serve as the entire universe of approaches to increase the number of patients placed on transplant waitlists. They can, however, serve as "tests of change" that drive performance improvement and quality improvement programs.

About QAPI: QAPI merges quality assessment (QA) and performance improvement (PI) into a comprehensive approach to quality management. QA is the process of meeting standards and ensuring care reaches an acceptable level. PI is the proactive, continuous study of processes with the intent to identify opportunities and test new approaches to fix the underlying causes of persistent, systemic problems. Data-driven QAPI programs may be customized to facility needs. Key steps include:

- Identifying the problem and defining the goal
- Deciding on a measurement to monitor improvement
- Brainstorming solutions based on barriers and root causes
- Planning an intervention
- Using plan-do-study-act (PDSA) to implement the improvement project

Learn more about QAPI: https://esrdnetworks.org/resources/toolkits/mac-toolkits-1/qapi-toolkit/qapi-toolkit

Dialysis facilities can contact their local ESRD Networks for assistance with PDSA principles and practices, questions about change strategies, and transplant-related resources. A complete listing of ESRD Networks can be found at http://www.esrdnetworks.org.

II. Change Package Methodology

The ideas presented in this change package were identified through extensive interviews with high-performing dialysis facilities. The facilities were selected utilizing waitlist data as documented in CROWNWeb. During the interviews, systemic themes emerged, which were organized into driver diagrams, visual displays of what drives and contributes to achieving an overall aim.[7] The diagrams include drivers and associated change ideas, which were reviewed by three nationally recognized nephrologists to ensure relevance to a broad range of dialysis facilities. The input of these experts was incorporated into the document.

III. Kidney Transplant Drivers

Interviews with high-performing dialysis facilities revealed primary and secondary drivers being used to increase kidney transplantation (Table 1). "Primary drivers are the most important influencers" that "contribute directly to achieving the aim." Secondary drivers are the actions and interventions that impact the primary drivers.[7]

The primary and secondary drivers as well as the associated change ideas included in Table 1 and in the driver diagrams, Tables 2–17, are not in ranked order. They are numbered for easy reference.

Table 1. Primary and Secondary Drivers to Increase Kidney Transplantation

AIM: INCREASE KIDNEY TRANSPLANTS	
PRIMARY DRIVERS	**SECONDARY DRIVERS**
1. Create a pro-transplant culture	1a: Link the organizational mission to the work 1b: Hire team members who will support a culture of caring 1c: Designate one or two champions to drive transplant efforts 1d: Engage all facility staff in improving transplant referral rates 1e: Engage patients in the transplant referral process
2. Implement continuous quality improvement	2a: Track transplant referrals and progress 2b: Engage physicians and staff in the review of data and the development of interventions 2c: Review transplant information with patients
3. Continually follow up on transplant status	3a: Hold informal discussions about transplant with each patient at every patient clinic visit 3b: Provide patients with knowledge, tools, and support to help them move the process forward 3c: Act as a case manager to facilitate progress 3d: Maintain communications with transplant centers
4. Educate and support patients	4a: Provide education early and regularly on transplants and the transplant process 4b: Offer support throughout the referral process 4c: Facilitate patient-to-patient support
5. Provide staff education	5: Provide education to maintain staff knowledge on transplants and the transplant process

IV. Key Change Ideas

The following driver diagrams (Tables 2–17) expand on the kidney transplant drivers (Table 1) and include specific change ideas for all the secondary drivers identified by high-performing dialysis facilities. The visualizations show the relationships between the primary and secondary drivers and the associated change ideas.

Table 2. Link the Organizational Mission to the Work

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1a: Link the organizational mission to the work
When an organization promotes transplants as part of its mission, that message filters throughout the organization, guiding staff as they perform their work and generating momentum among staff and with patients for continuous improvement. **Change Ideas** 1. Keep the focus on the mission statement. a. Discuss it monthly with staff. b. Share it freely in email communications. c. Lead by example – key leaders (e.g., nephrologist, administrator) live the mission/culture. "This is our whole life. This is what we do." 2. Constantly talk about transplantation – "The language of transplant is always there at the core."

Table 3. Hire Team Members Who Will Support a Culture of Caring

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1b: Hire team members who will support a culture of caring
Evaluating potential new hires to see if they are a good fit will ensure everyone contributes to a culture of caring. **Change Ideas** 1. Set clear expectations during the interview – staff must be dedicated to the craft, treat patients with respect and dignity, and hold a philosophy of patients first. 2. Utilize administrative staff and peers for interviews.

Table 4. Designate One or Two Champions to Drive Transplant Efforts

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1c: Designate one or two champions to drive transplant efforts
Commonly, facilities with success in referring patients for transplant had one or two persons leading the charge, whether the persons were formally designated as Transplant Designee/Manager or they grew into that role organically from their passion for transplants. As one staff member said, "I just want them all to get kidneys. I can get another job." **Change Ideas** 1. Determine who has an interest and passion for promoting transplants. 2. Consider all staff as possible champions, e.g., physician, social worker, and unit secretary. 3. Make the position a formal role. 4. Ensure the champion is educated in general listing criteria for transplant centers, so potential barriers can be discussed with patients.

Table 5. Engage All Facility Staff in Improving Transplant Referral Rates

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1d: Engage all facility staff in improving transplant referral rates
All facility staff play a role in getting patients on the transplant waitlist. This is especially true of nurses and patient care technicians (PCTs) who have established relationships of trust with patients. These frontline staff can promote transplant, listen to patient concerns, and communicate barriers and questions to the rest of the team. **Change Ideas** 1. Set the expectation for the staff upon hire and during on-boarding that transplant referral is a priority for all patients unless contraindicated. 2. Give each staff member a defined role in the referral process, such as the PCT being responsible for drawing the blood sent to the transplant centers every month. 3. Incorporate transplant referrals into weekly staff meetings or emphasize and track referrals during QAPI meetings to include a review of who has not been referred and who has been removed from a waitlist. 4. Keep staff informed of patient goals related to transplant, e.g., through IDT rounds. 5. Enhance communication among staff a. Use daily huddles to discuss patient updates. b. Co-locate staff in close proximity to facilitate the exchange of information on a real-time basis. c. Maintain continuous team communication through daily discussions and documentation. 6. Provide a channel of communication for the frontline staff, encouraging them to give feedback and provide recommendations. 7. As a shared success, celebrate patients who receive an offer for a transplant or who have had a transplant. 8. Dedicate an area on a bulletin board to display a star for each patient who receives a transplant each year.

Table 6. Engage Patients in the Transplant Referral Process

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1e: Engage patients in the transplant referral process

Engaging patients in their own care enhances their understanding of the transplant process and provides them with opportunities to share their questions and concerns about transplants. Patients can then make fully-informed decisions about whether or not they want a transplant.

Change Ideas

1. Introduce transplant during the first meeting with the social worker or facility staff; then, follow up timely (e.g., in a week or at 30- and 90-day assessments, depending on the patient's readiness to discuss transplant) and regularly during clinic visits.
    a. During initiation of dialysis, approach the patient with the message, "Dialysis is used as a bridge to transplant." Emphasize the temporary nature of dialysis by including the message monthly.
    b. Determine the patient's readiness to discuss transplantation and his/her knowledge base.
    c. Discuss the patient's family support, transplant options, living donors, transplant centers, and requirements.
2. Explore the real "why" a patient is not interested in transplant by establishing relationships, building trust, and using open dialogue.
3. Involve the family and support system in the education.
4. Encourage the patient to attend kidney symposiums to hear speakers on transplant.
5. Find out reasons a patient could be motivated to get a transplant, (e.g., family, travel, lifestyle) and incorporate the motivators into discussions.
6. Re-visit transplant when the patient is better able to receive the information, e.g., after uremia is resolved.
7. Discuss transplant during yearly psychosocial evaluations, if the patient has indicated he or she does not want a transplant.
8. Share an educational video with in-center patients on transplant, including deceased and living donor options and living donor champions.
9. Let the patient know he or she can get the evaluation and make the final decision about the transplant later.
10. Share transplant successes of other patients. Invite patients with transplants to visit the facility and speak with patients.

Table 7. Track Transplant Referrals and Progress

PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT
Secondary Driver #2a: Track transplant referrals and progress

Quality improvement cannot occur without measurement. Facilities that are successful in referring patients for transplant track transplant metrics as well as each patient's progress with the referral process.

Change Ideas

1. Collect data on metrics, including the number of patients referred to transplant centers, the number of patients who are active, and the number of patients who have been removed from waitlists. Include these as elements of the QAPI plan.
2. Use electronic tools accessible to staff to track each patient's waitlist/transplant status.
    a. Document details in each patient's electronic health record (EHR).
    b. Use dialysis-specific software with reminders or a webtool, such as "Helping Hands."
    c. As a supplement to the EHR, if needed, track patients' information in an Excel spreadsheet.
3. Use reminders in electronic tools to trigger follow-up conversations with patients.
4. Ask physicians to include transplant status in their notes from weekly rounds. Remind physicians that Transplant Status and Plan is one of the components of the Monthly Comprehensive Plan.
5. Maintain transplant binders. Examples include:
    a. A transplant referral binder, tabbed by patient name, with all correspondence to and from the transplant centers, such as waitlist status and notices of upcoming appointments.
    b. A binder with information on all patients on active waitlists.
    c. A binder of information on patients who are not on waitlists, so the staff can re-visit later.
6. Document transplantation in psychosocial evaluation and progress notes, including transplant status, monthly updates, tests needed, and questions to ask the patient at the next visit.
7. Obtain lists of patients on waitlists from transplant centers.

Table 8. Engage Physicians and Staff in the Review of Data/Development of Interventions

PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT
Secondary Driver #2b: Engage physicians and staff in the review of data and the development of interventions

Including physicians and staff in the review of data allows for robust root cause analyses, brings real-world perspectives to the development of interventions, and reinforces the philosophy that "We are all in this together."

Change Ideas

1. Commit to quality improvement.
2. Set a goal for improving the percentages of patients on a waitlist with a specific time frame, e.g., monthly or quarterly.
3. Incorporate transplant metrics and discussions into every monthly QAPI meeting.
4. Include frontline staff in QAPI meetings, rotating different staff each month.
5. Hold a brief huddle after each QAPI meeting to review highlights of the QAPI meeting with staff who did not attend.
6. Determine the root causes if metrics were not met and develop interventions to improve performance.
7. Include a review of transplant data weekly in staff meetings and monthly with nephrologists.
8. Review the transplant log to identify barriers to maintaining waitlist status, such as missed appointments, monthly.
9. Review lists of patients from transplant facilities to verify waitlist status monthly.
10. Identify interventions to facilitate patients being added back onto a waitlist, such as referring a patient dropped from one list for age to a different transplant center that accepts older patients.

Table 9. Review Transplant Information with Patients

PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT
Secondary Driver #2c: Review transplant information with patients

Sharing lab results and other data with patients deepens their engagement in their own care, reinforces the importance of continual vigilance to stay healthy and transplant-ready, and gives them the information they need to actively participate in maintaining active status on the waitlist.

Change Ideas

1. Review patient lab results each month, discuss how the results affect transplant suitability, and make adjustments as needed to ensure the patient is transplant ready.
2. Share details from the transplant log (e.g., letters from the transplant center) monthly and discuss next steps to ensure the patient clearly understands where he or she is in the process of evaluation and/or listing.

Table 10. Hold Informal Discussions with Each Patient at Every Patient Clinic Visit

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3a: Hold informal discussions about transplant with each patient at every patient clinic visit
Weaving transplant discussions into care processes provides an efficient means for staff to obtain updates from patients on transplant status (e.g., waiting for Medicare coverage), answer questions (e.g., what should be done next?), and collaborate with patients on solutions to challenges they may be experiencing (e.g., delays in evaluation by the transplant center). **Change Ideas** 1. Have a conversation with each patient about transplant and waitlist progress during all aspects of care, including physician rounds, patient care by nurses and PCTs, and meetings with social workers. a. Determine the frequency of the transplant discussion, e.g., a discussion will occur monthly with the physician. b. Use open-ended, conversational questions, such as, "Where are you with your transplant?" and "How's the transplant evaluation going?" 2. Encourage patients to have the transplant evaluation early in the process, so they can be the best version of themselves. 3. Identify obstacles to maintaining waitlist status or completing a transplant evaluation.

Table 11. Provide Patients with Knowledge, Tools, and Support

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3b: Provide patients with knowledge, tools, and support to help them move the process forward

When patients know what to expect and what they can do related to the transplant process, whether completing referral forms or connecting with transplant center coordinators, they take a more active role. Actively engaged patients can speed up the referral and evaluation processes, identify challenges early, and maintain their waitlist status.

Change Ideas

1. Give the patient transplant educational materials, beginning with the first visit.
2. Assess insurance status and advise the patient to apply for Medicare, as applicable.
3. Share information on the requirements of the referral process, so the patient can prepare, e.g., line up transportation and schedule a dental exam or mammogram. Check with the ESRD Network to see if it has a patient guide to the referral process.
4. Inform the patient in writing when he or she has been referred to a transplant center.
5. Share an educational video with in-center patients on navigating the transplant process.
6. Share the transplant center contact information with the patient. To avoid missed calls, help him or her, if needed, to program the transplant center number into his or her phone.
7. Encourage the patient to call his or her transplant coordinator regularly. Help the patient find out who the coordinator is.
8. Provide the patient with a referral form that has a list of criteria for each transplant center. To avoid duplication of efforts, contact the ESRD Network to determine if it has compiled a list of criteria by transplant center.
9. Support the patient with the completion of paper-based and online referral forms.
10. Encourage the patient not to wait on the transplant team but to call and ask, “What do I need to do next?”
11. Teach the patient how to stay healthy (e.g., not smoking) to maintain active status on the waitlist.
12. Use analogies to connect with the patient, e.g., “play the best odds” for “a transplant will improve your chances of survival” or “keep the car running” for “you have to stay healthy while waiting for a kidney.”
13. Refer the patient to clinical and support services, so he or she can take an active part in removing modifiable barriers to transplant, e.g., working with a dietitian on weight loss or getting treatment for mental health issues.
14. Encourage the patient to list with more than one transplant center.
    a. Create a “book of transplant centers” that includes the requirements/criteria, patients referred, and patient status.
    b. Share transplant center requirements with the patient.

Table 12. Act as a Case Manager to Facilitate Progress

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3c: Act as a case manager to facilitate progress
Staff at successful facilities took on a role resembling case manager to assist patients and caregivers in navigating the complicated transplant process. **Change Ideas** 1. Collaborate with the nephrologist to identify transplant centers that would best meet the patient's needs (e.g., high body mass index [BMI] or specific type of insurance) or that accept a patient who does not qualify elsewhere (e.g., a patient with Sickle Cell Disease). 2. Call the social worker (transplant champion) if the patient indicates he or she has not been referred or evaluated and to help resolve barriers. 3. Refer the patient to clinical and support services, as needed, to address modifiable challenges, such as smoking. 4. Determine why a patient has been deferred or removed from a waitlist and identify possible solutions. 5. Intervene on the patient's behalf to resolve barriers, e.g., "The transplant team won't call me back." 6. Help solve transportation problems by exploring options, e.g., neighbors, church members, ride sharing, and government assistance programs. 7. Extend problem-solving to include family when issues may impact the patient's comfort level with being on a waitlist or receiving a transplant, e.g., identifying social services support for a family member who would be left alone during the transplant procedure.

Table 13. Maintain Communications with Transplant Centers

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3d: Maintain communications with transplant centers
Open, continuous communication between dialysis facilities and transplant centers supports collaborative efforts to get patients onto waitlists. **Change Ideas** 1. Establish relationships with the transplant center coordinators and actively collaborate with them. a. Call to introduce the staff and the facility. b. Exchange cell phone numbers to expedite communication. c. Schedule quarterly transplant center staff visits to the dialysis facility. 2. Contact the transplant center to determine requirements for lab tests. 3. Call the transplant centers before facility meetings to discuss the status of patients on the active waitlist and reasons for patients being placed on hold. 4. Intervene on the patient's behalf, e.g., to have the patient put on hold instead of being removed from the waitlist and to see what can be done to speed up the waitlist process. 5. Make sure transplant centers have accurate patient phone numbers and other information by providing new information if the patient changes phone numbers or after quarterly updates to patient demographics. 6. Facilitate communication between the transplant center and the patient when the transplant center cannot reach the patient. 7. Contact the transplant center directly upon receipt of a denial letter or if an update has not been received in one to two months. 8. Engage the medical director to establish and maintain relationships with transplant centers and surgeons and to negotiate for the patient on exclusion criteria, e.g., BMI or marijuana use. 9. Call the transplant center's medical director, if necessary, to resolve issues.

Table 14. Provide Education Early and Regularly on Transplants/Transplant Process

PRIMARY DRIVER #4: EDUCATE AND SUPPORT PATIENTS
Secondary Driver #4a: Provide education early and regularly on transplants and the transplant process

Patients who understand what a transplant is and what to expect during the referral process and after transplant will be able to make informed decisions about whether to have a transplant. They will also be better prepared to complete all of the requirements of the referral process.

Change Ideas

1. Give the patient easy-to-read and easy-to-understand transplant educational materials, beginning with the first visit, e.g., transplant booklet from a provider.
2. Conduct formal education sessions, e.g., Kidney Smart classes every month.
3. Meet with the patient individually to answer questions.
4. Spend additional time with the patient who is reluctant to have a transplant to address misunderstandings about transplants and discuss the benefits, including improved quality of life and survival rates.
5. Incorporate education into discussions with the patient, such as what will happen next in the transplant process and what he or she can expect after transplantation.
6. Put up a bulletin board/education station in the lobby with transplant information to promote questions and interest.
7. Provide additional formal education semi-annually.
8. Share transplant center educational materials with the patient.

Table 15. Offer Support Throughout the Referral Process

PRIMARY DRIVER #4: EDUCATE AND SUPPORT PATIENTS
Secondary Driver #4b: Offer support throughout the referral process

The transplant waitlist process can be overwhelming to patients and members of their support systems. Providing support will help patients stay on track and maintain active waitlist status.

Change Ideas

1. Let the patient know "We are your family": Build trust every day. Show sincerity. Maintain open communications. Follow up with the patient and follow through to show that a transplant is important.
2. Communicate through the team member with whom the patient feels most connected, e.g., PCT or nurse or dietitian.
3. Help the patient to identify members of his or her support system not previously considered, e.g., neighbors, friends, and church members.
4. Offer support to the family or members of the support system.
5. Give the patient access to nurses, social workers, and dietitians by phone to help him or her stay medically stable and troubleshoot barriers.

Table 16. Facilitate Patient-to-Patient Support

PRIMARY DRIVER #4: EDUCATE AND SUPPORT PATIENTS
Secondary Driver #4c: Facilitate patient-to-patient support
Patients who have received a transplant serve as powerful and trusted advocates of transplants. They can allay other patients' fears and answer questions. Patient representatives who are receiving dialysis can also offer peer support to other patients. **Change Ideas** 1. Utilize patients with transplants as mentors to encourage and empower others by inviting them to speak with patients or to join lobby days. 2. Share information about patient support groups and educational meetings that highlight transplantation topics and testimonies about patient success. 3. Engage patients who are receiving dialysis to act as facility patient representatives to educate other patients about transplants and provide peer support.

Table 17. Provide Education to Maintain Staff Knowledge

PRIMARY DRIVER #5: PROVIDE STAFF EDUCATION
Secondary Driver #5: Provide education to maintain staff knowledge on transplants and the transplant process

Staff who are knowledgeable about transplants will be able to answer patients' questions, promote transplants, and educate peers.
 	
Change Ideas
1. Utilize the transplant champion (e.g., facility administrator) to educate staff.
2. Hold brief huddles or on-the-spot conversations during teachable moments to convey information timely and efficiently.
3. Conduct educational webinars and in-services regularly with staff.
4. Share literature with staff about new technologies.
5. Invite patients who have received a transplant to speak with staff about their experiences.
6. Collaborate with transplant centers on education.
  a. Invite transplant centers to conduct in-services with facility staff or hold lobby days where facility staff can interact with transplant center staff.
  b. Have staff join the patient on the first work-up day at the transplant center.
7. Encourage professional certification, e.g., Certified Hemodialysis Technician (CHT) and Certified Nephrology Nurse (CNN).
8. Have staff attend conferences (e.g., American Nephrology Nurses Association [ANNA]) and share information with colleagues.

V. Conclusion and Next Steps

Increasing kidney transplantation is a national priority. Dialysis facilities play a central role in helping more patients with ESRD understand their treatment options with a hope of a higher quality of life. A concerted effort is needed among all kidney care stakeholders to meet the bold goals set by the HHS Advancing American Kidney Health Initiative. The change ideas presented in this change package are being implemented in high-performing dialysis facilities across the United States. These ideas can be tailored and adapted to fit the needs of dialysis facilities and the patients with ESRD that they serve across the country.

As with any change, a best practice is to start small and build improvement toward systemic change. Facilities can start with one test of change and do it well. This will relieve the burden on staff and encourage buy-in when change begins. Measuring and monitoring performance improvement will ensure the facility stays on track with goals. Celebrating every success with staff, patients, families, and community partners at every change will be contagious. Above all, the best time to start performance improvement is now. With this change package in hand, program leaders, administrators, and staff should ask themselves, “What can I do by next Tuesday to get this started?”

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