

Derek and Sophie ASH Discussion

- Start with introductions and each tell the story of how we ended up caring for people with SCD
- Discuss what factors were helpful in starting the relationship
 - Clinician willing to step out of the clinic to educate other clinicians and the community when invited by CBO
 - CBO partner who recognizes the need to advocate for the entire community. One that is willing to listen and understand clinician perspective.
- CBO and Clinicians should have some similar goals for the sickle cell community
 - Important to discuss goals—can't assume that they are the same
 - Each recognize that there are scarce resources, often multiple CBO's competing for those resources
 - As a clinician/academic institution, can recognize those CBO's that are willing to involve others and engage the entire sickle cell community
 - Can't fix all of the CBO issues (and it's not academic job)
- Not all resources provided to CBO's by clinicians/academics are financial
 - Providing space for support groups
 - Support group then run by CBO and not by clinician
 - Advertising support groups and letting patients know about CBO
 - Being available to speak at CBO activities
- Grants
 - Clinicians can write letters of support for CBO grants
 - Many grant agencies for academics now require patient/stakeholder engagement
 - Important when academics include CBO in grants that they respect time and ensure there is financial compensation for participation
 - When we started:
 - Initial grant was to have Derek on advisory committee for stakeholder input
 - Now grants include capacity building and include MSCDA providing services to the patients we serve
 - CHW's
 - Transportation, food, and job training
 - When doing more complex grant with CBO, it's worth educating on details of the budget
 - Fringe, indirect rate, and %FTE—define these
- Do not underestimate the power of advocacy by CBO's (UMCR example of such advocacy)
 - Ask CBO's to help with advocacy in your institution if needed
- Challenges: There will be some
 - Relationship must have a strong foundation
 - Develop relationship before there is a crisis
- Providing support to CBO's
 - CBO ECHO
 - Several CBO's where leadership can provide mentorship to your local CBO's
 - These mentors can:

- Help navigate difficult relationships that might exist between your institution and CBO
- Help your local CBO be more effective, help with capacity building