



Proposal for a telehealth-based system of care

1. The Medical home concept is re-envisioned as a Medical Hub providing structure and communication networks to the specialists who become the patient's Medical Ohana. In the words of Stitch, from the movie **Lilo & Stitch**, "Ohana means family. Family means no one gets left behind."An illustration of the characters Lilo and Stitch from the Disney movie 'Lilo & Stitch'. Lilo is a young girl with dark hair, wearing a red and yellow patterned dress, hugging Stitch from behind. Stitch is a blue, alien-like creature with large ears and a small body.

 - a. Hub the expertise and use telemedicine technology to deliver specialized and supportive care to the family in their actual home or in a community-based site.
 - b. As much as possible, care will be delivered to the patient in the least restrictive settings including but not limited to the family's home, the patient's school, and primary care providers, and Emergency departments in outlying communities.
 - c. Care coordinators can help with the logistical burden of coordinating the services provided by the Medical Ohana through the Medical Hub. When appropriate, the Care coordinator can participate in the telemedicine sessions to ensure medical recommendations are followed, and follow up appointments and additional referrals are arranged for the patient and family.
 - d. Other family members can participate in sessions via telemedicine from their workplace or another city.
 - e. Translators and sign-language interpreters can be added to telemedicine sessions from a variety of web-based providers.

2. Decrease the burden of care imposed by logistics.
 - a. The cost of care is not just the medical fees. The other costs include the opportunity cost of attending a medical appointment. These costs include the time the family spends getting to appointments, time one or more parents are not working, time spent worrying if a symptom needs medical attention, school absences, and time away from the activities of daily living.
 - b. Decrease no show rate by coming to the patient where they live, study, and play.
 - c. Improve the logistics of providing specialist expertise on demand instead of buying



- blocks of time or complex employment logistics.
- d. Expanding the specialized organization to reach a larger geographic range of the target population without building more brick and mortar and staffing the satellite offices.
 - e. Lastly, what is the value of decreasing family stress? Caring for a special needs patient is very stressful for the parent(s) and causes a high rate of caretaker burn out, family discord, and divorce. Telemedicine will decrease the family's stress and improve the family's quality of life. By decreasing the family's barriers to accessing care, they will receive medical attention before minor symptoms escalate into crises.
3. Multiply and leverage the physicians by having them supervise and collaborate with a variety of ancillary staff, community practitioners, and trainees.
- a. Integrate students and trainees into service provision. Expand the range of socioeconomic groups, cultures, and clinical conditions they can learn about during training. Telemedicine will help them work in remote areas and maintain patient continuity without long travel times. Telemedicine will improve the flexibility of the training schedule so students can see patients, receive supervision, and attend lectures at many locations without leaving their office.
 - b. Teach trainees verbal and nonverbal telemedicine communication strategies so they are ready to use this technology in their professional practice.
 - c. Specialists can provide consultations and supervision to trainees at any Hub site where the trainee is working with the special needs patient and families.
 - d. Telemedicine makes it easier for specialists to provide routine and urgent consults to community practitioners. This will improve the community provider's capacity to handle more complex patients.
4. Benefits to the patient of integrating mental health
- a. Goals will be family centered respecting what is valuable and meaningful to the child and family within the limits of law and medical ethics.
 - b. Improve Quality of Life indicators, many of which are influenced by self-perception, stress management, and confidence.
 - c. Improve patient and family's resilience and ability to perceive difficult and stressful events as challenges to overcome with the support of their Medical Ohana.



- d. Improve self-confidence and diminish the patient's focus on his or her limiting factors, despite the time and energy required to manage the disability or condition. Help the patient develop a self-image that is based more on his or her strengths instead of his or her disability or chronic illness. Nurture his or her capacity for self-determination and an active role in treatment planning and implementation.
- e. Ensure a youth progresses in his or her emotional development, rather than allow trauma, disease, stress, and anxiety to restrain emotional maturation.
- f. Improve family functioning and help families avoid the common dysfunctional reactions to raising a special needs child. These include fragile child syndrome, dependent personalities, excessive blame and guilt, relative neglect of the neurotypical sibling(s), caretaker burn out, and parental divorce.
- g. Improve the youth and family's networking with community resources. When intellectually and emotionally appropriate, the youth should participate in advocacy and support groups with other youth and families.
- h. Improve the capacity of youth, specialist, and family to understand and contribute to the development of school and vocational accommodations and goals. This will improve the quality and appropriateness of Individualized Educational Plans (IEP), Individual Support Plans (ISP), and Vocational programs.
- i. CBT principles to decrease helplessness, and improve a positive sense of future, and a sense of control and self-reliance (with accommodations.)
- j. Improve social skills for the youth by teaching them social strategies using specialized curriculum delivered by interactive videoconference. The older teenagers and young adults will progress to similarly specialized friendship and dating programs.

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