

Charter for Interactive Autism Network Community Advisory Council

Draft Version 1.0 – March 2016

Mission of the Interactive Autism Network (IAN)

The mission of IAN is to improve the lives of individuals with Autism Spectrum Disorder (ASD) and their families by facilitating research that will lead to advancements in the understanding and treatment of ASD. To accomplish this mission, IAN works to accelerate autism research, engage families and individuals with ASD as partners in the research process, improve the return on investment of other autism research projects, contribute directly to scientific knowledge, and facilitate the distribution of information to the public.

Long-term Goals

Over the next decade, IAN will advance research and facilitate public policy efforts by doing the following:

- Engaging a broad range of families and individuals with ASD in autism research by designing and implementing new user-centered survey research interfaces and continuing innovative public education activities.
- Developing technologies that will provide families with access to useful personal health information derived from IAN Research instruments that can be shared with care providers, saved for their records, and integrated into other health, education, and research systems.
- Enhancing study recruitment services by providing researchers with technologies that will help them track recruitment activities, better engage potential participants through automated contact options, and access data about potential participants.
- Expanding the collection of community-reported information to inform ASD research.
- Enhancing data linking and integration practices through collaborative, large-scale initiatives with other national ASD clinical and research networks.
- Developing and implementing technologies that will allow IAN to provide online services for the execution of clinical trials.

Purpose of Community Advisory Council

The purpose of the CAC is to help represent the autism community in the process of autism research by providing advice and assistance to the Director of the Interactive Autism Network (IAN) in his responsibilities to develop and execute strategy and programs.

Structure

The committee will consist of up to thirty members and have two arms: Primary and Satellite.

The Primary arm will have up to ten members who participate in quarterly conference calls or online meetings to discuss how IAN's research agenda can better serve the autism community and engage more participants in autism research. Primary members will be able to participate in Satellite activities.

The Satellite arm will have up to twenty members. They will help IAN test research surveys, take informal surveys and polls, and participate in online focus groups. Members of this group will be asked to participate in at least two activities per year, though more than two activities will be available to them.

The authority to select the members of the Council is delegated to the Director, and the members will be invited to serve for two year terms.

Meetings

Meetings of the Primary CAC will be held four times a year by conference call or online. The Director of IAN will prepare and distribute an agenda after he has solicited input from CAC members.

Minutes will be kept at all meetings. Attendance will be called at all meetings and reported in the minutes. The Director of IAN is responsible for distributing the minutes to all Primary CAC members and to organization officers when requested.

No formal meetings will be held for the members of the Satellite CAC, but they will be asked to participate in asynchronous activities such as surveys and polls, or online focus groups.

Staff will provide all CAC members with an annual report informing them of IAN's activities.

Compensation

Participants in the Primary CAC and the Satellite CAC will receive a gift in the form of a gift-card or similar compensation for their term of participation and contribution to IAN.