

**Q1** Please provide your contact information below.

Name	
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**Q2** Please describe your company or organizations overall goals and mission.

We are a multi-faceted organization with programs and services authorized by OPWDD, OASAS, OMH, ACCES-VR and NYSED. Our mission is to provide people with disabilities and other developmental challenges support to attain independence, self-determination, integration and acceptance by others through education, exploration and experience.

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**Q3** Please indicate which category your organization falls under. **Community Based Organization**

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**Q4** Innovation Executive Summary. Please describe the innovation, and how it addresses the social determinants of health. Please identify how the innovation addresses the 6 innovation criteria (i.e. ROI, scalability, feasibility, evidence based support for innovation, relevance to the Medicaid population and speed to market).

Self-Determination among Adults with IDD Living in Congregate Care Settings as a Social Determinant of Health

Social Determinants of Health as categorized by NYSDOH include four (4) determinants that are largely unimportant for adults with intellectual and developmental disabilities living in congregate care settings and one that we believe is highly relevant: Social & Community Context. Adults with IDD living in congregate care settings have completed Education, have Health Care coordinated by the provider agency, have stable Housing and have basic Economic needs met. A body of research and our professional experience conclude that many adults with IDD experience limited or no self-determination (Stancliffe, 2001; Whemeyer, 2001), and those who exhibit self-determined behavior are likely to experience higher levels of life quality than those who do not. Quality of life is likely associated with better health and behavioral health outcomes. The basic theoretical model for our innovation project looks like this: Self-Determination → Quality of Life → Better Health Outcomes.

For the purpose of this innovation project, we define self-determination as “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). While many adults with IDD living in congregate care settings experience limited self-determination, there are environmental factors that can support growth of or inhibit adoption of self-determined lifestyles (Nonnemacher & Bambara, 2011). Staff actions that inhibit self-determination may include: usurping decision making and control, controlling personal spending, being unapproachable or inaccessible, failing to follow through on personal requests or expressions of personal interest and obstructing or coercing. Staff actions that support self-determination may include: expanding options and experiences to encourage choice, supporting access to people of authority to get voice heard, being approachable or accessible, listening without judgement, and providing support for follow through.

The purpose of this innovation project is to demonstrate that implementation of a specific program to promote self-determination can not only enhance quality of life for people with IDD but can also result in better health and behavioral health outcomes. Although people with IDD represent a small segment of the Medicaid population, many are among the highest or most frequent users of health care services (i.e., super-users). People with IDD have higher rates of psychiatric disorders, physical and mobility disorders, oral health concerns and obesity than the general population (Anderson et al., 2013; Traci et al., 2002). They have also been noted to lead sedentary lifestyles in general (Peterson, Janz, & Lowe, 2008) and take 6.5 prescription medications on average per person (Sisirak, Marks, Riley, & Chang, 2008).

After three years of planning, Abilities First launched its own unique Self-Determination Support Model in 2017. Although we have been accredited by the Council on Quality and Leadership (CQL) since 2012 and had adopted the principles and actions of CQL in order to promote self-determination, we recognized the need to go above and beyond CQL in several ways. 1. Formal CQL interviews to learn about what is important to a person happened 1-2 times per year and we wanted concrete systems to ensure incorporation of support for self-determination on a daily basis. 2. Structured CQL interviews are conducted by select and certified CQL interviews and we wanted all of our staff to draw upon the interview questions and incorporate these concepts in everyday interpersonal interactions. 3. We wanted a concrete method for documenting expressions of personal interest or requests regardless of where/when they occurred and who happened to be with the person to witness them, so we created a form for this which is being transformed into an app for smartphones and tablets so it can be completed by all staff anytime anywhere. 4. We wanted a method to ensure follow through on expressions of personal interest so we created a routing procedure that moves the completed forms higher in the organization until they are resolved, and we enlist the help of our organization’s risk management committee when such requests or expressions involve some kind of risk or significant obstacle.

To date, we have processed and resolved approximately 80 personal requests that have resulted in better family relations, moves to lesser restrictive residential settings, getting jobs, planning vacations, for example. Through this innovation pilot we would like to analytically connect implementation of our Self-Determination Support Model with enhanced Quality of Life and improvement in health and behavioral health outcomes.

Potential Return on Investment – Abilities First has already invested in consultants, development and branding of the model, launch and initial implementation of the model. Additional investment is needed to finalize development of the app, conduct efficacy study, and create final package for the model and its materials. Total estimated cost for these steps is estimated to be fractions of the potential return from improved health outcomes, transitions of people to lesser restrictive and less costly settings, and potential reductions in residential staffing across the state system.

Scalability – This innovation project could easily be brought to scale rather quickly across the state with proliferation of the app and delivery implementation guidelines for the model.

Feasibility – The majority of innovation in this model is in the mapping of process to the theoretical model that is supported by research and evidence. Actual implementation means fidelity to the model which should be considered naturally feasible.

Evidence-based support for innovation – We believe the narrative in this executive summary provides adequate indication of evidence supporting the innovation project.

Relevance to the Medicaid Population – While this innovation project is designed specifically for the IDD population, systems for

supporting self-determination can be applied to other Medicaid populations.

Speed to market (how quickly could the strategy be launched) – We believe the final steps to completion and launch would take roughly 3-4 months.

#### References

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- Peterson, J. J., Janz, K. F., & Lowe, J. B. (2008). Physical activity among adults with intellectual disabilities living community settings. *Preventative Medicine, 47*(1), 101-106.
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- Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 91-98.
- Traci, M. A., Seekins, T., Szali-Petree, A., & Ravelsloot, C. (2002). Assessing secondary conditions among adults with developmental disabilities: A preliminary study. *Mental Retardation, 40*(2), 119-131.
- Wehmeyer, M. L. (2001). Self-determination and mental retardation. In M. L. Glidden (Ed.), *International review of research in mental retardation* (Vol. 24, pp. 1-48). San Diego: Academic Press.
- Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities, 30*, 113-120.

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**Q5** Was your innovation implemented? If so, please explain when, the number of people impacted, and the results.

Yes (please specify when and the estimated number of people impacted):

Our innovation project has been partially implemented. We have used the innovation to impact 80 people by supporting self-determination, expanding social opportunities and satisfaction.

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**Q6** Please identify the SDH Domain that your innovation addresses. (Select all that apply.)

**Social and Community Context**

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**Q7** I give the Department of Health the right to share the information submitted in this application publicly (for example: on the DOH website). I understand that there is no monetary reward/reimbursement for my submission or for attending the summit should my innovation be selected.

**I consent to have my innovation shared**

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