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Design of a Tool to Reduce the Number of Preventable Doctor/Hospital Visits Experienced by Individuals with Intellectual and Developmental Disabilities (IDD)

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Abstract: In the US there are over 2 million individuals with Intellectual and Developmental Disabilities (IDD); these are lifelong conditions causing limitations and complex health issues that often require assisted living support. One characteristic of individuals with IDD is non-verbal communication; they may be limited to one-word phrases or gestures. The limits in communication present a problem communicating health and wellness conditions. This leads to individuals with IDD experiencing 3-4 times more preventable doctor and hospital visits than the general population. Currently, early, mild symptoms often go undocumented, allowing them to "snowball" into severe episodes. This paper describes the design and operation of a tool to record behavior and symptoms over time and alert caregivers for combinations of behaviors/symptoms associated with medical conditions requiring care. A stochastic simulation of condition progression showed a reduction in mean doctor visits from 9.186 per patient per year to 5.2 per patient per year.

Keywords: Intellectual and Developmental Disability (IDD), Assisted-Living Facilities, Direct Support Professionals (DSPs), Proactive Care, Health Monitoring

1. Ecosystem

The United States healthcare system supports over 2.2 million American adults with Intellectual Developmental Disabilities (IDD). This includes conditions such as Autism, Cerebral Palsy, and Down Syndrome. Many of these individuals reside in licensed group homes and assisted living facilities which provide Long-Term Support Services (LTSS) to residents (Helperssf, 2025).

This paper serves to present the design of the functional prototype called CareAble: a digital health platform engineered to bridge the gap across care teams and residents with IDD living in assisted living facilities and group homes. CareAble brings transparency across care teams through standardized daily health observation logs, and the use of an automated predictive alert system to help enable care teams with a data-driven approach to proactive interventions with their residents. The platform also provides DSPs with a checklist to record behaviors and symptoms over time which provides the basis for alerting healthcare professionals of emerging medical conditions before they occur. This paper also presents a simulation to evaluate the potential impact of resident health monitoring on symptom progression and care costs for individuals with intellectual and developmental disabilities (IDD).

2. Stakeholders

The main stakeholders in the IDD care ecosystem can be grouped into two categories: (1) direct users and beneficiaries, (2) institutional regulators. A summary of stakeholders can be seen in Table 1.

Table 1. Stakeholder Summary

Stakeholder Group	Key Actors	Primary Objectives	Key Challenges
Direct Users & Beneficiaries	Individuals with IDD	Receive high standards of care and achieve improved quality of life	Communication barriers, especially for non-verbal individuals; lack of systematic health tracking
	Direct Support Professionals (DSPs)	Provide daily care, monitor symptoms, administer medication	Trouble understanding residents, high turnover, limited training
	Family	Stay informed and support long-term well-being	Delayed or incomplete updates; limited involvement in care decisions
	Doctors	Develop and adjust treatment plans	Lack of real-time and longitudinal data; reliance on fragmented reports
	Nurses	Oversee care delivery and support DSPs, coordinate treatment changes	Limited visibility due to incomplete documentation; dependence on DSP-reported data
Institutions & Regulators	Facility Administrators	Ensure compliance and maintain quality of care	Lack of real-time oversight, staffing challenges
	State Agencies	Enforce regulations and oversee care standards	Resource constraints, difficulty enforcing new regulations
	Federal Agencies (CMS)	Promote value-based care and regulate systems	Limited funding, developing new policies
	Managed Care Organizations (MCOs)	Fund and manage healthcare services	Delays in waiver approvals; administrative complexity affecting care access

3. AS-IS Process

The AS-IS process for mapping the IDD healthcare delivery process was developed through a combination of stakeholder interviews and facility observations to help accurately depict the present-day practices captured within assisted living facilities. Overall, the AS-IS process captures how resident behaviors and symptoms are currently observed, documented, and communicated across care teams.

Identifying Symptoms: DSPs are the primary observers of resident health status; they document behaviors and any physical symptoms in residents. However, many individuals with IDD have communication support needs (CSN) and may rely one single words or gestures. Therefore, DSPs heavily rely on visual cues and limited verbal feedback by their residents making critical signs such as changes in sleep pattern, appetite, or mood swings going unnoticed, and therefore undocumented across shifts (García et al., 2025). For the IDD population, their care team particularly focus on the following set life-threatening conditions known as the "Fatal Five": aspiration, constipation, dehydration, seizures, and sepsis. These conditions are leading causes of preventable morbidity and mortality in the IDD population. The early signs and symptoms of each the fatal five can be subtle and are often linked to the individual previously presenting symptoms. For example, dehydration may have been presented as tiredness or not being hungry. Since residents have limited ability to communicate discomfort or pain, these early symptoms are often the only signs available to DSPs before conditions worsen. Thus, without consistent monitoring and documentation of observable symptoms across shifts, symptoms and behaviors escalate into conditions that require treatment.

Adjusting Treatment Plans: Medical providers make treatment decision based on fragmented, often outdated information from different sources across a care team. There is a lack of longitudinal data for providers to complete an accurate assessment of treatment effectiveness in patients with IDD, resulting in 3-4 times more preventable hospitalizations compared to the general population ("A National System for Monitoring", 2021). The current AS-IS process for IDD healthcare promotes significant challenges in the quality of care provided to residents. Not catching symptoms is a fundamental cause of later, serious and preventable cases of patient harm within the IDD healthcare system. When health crises occur, reactive care is typically applied. Ultimately, this leads to significant financial burdens in patient care as residents are hospitalized in preventable instances. This is especially seen as the average cost of hospitalization for Ambulatory Care-Sensitive Conditions

(ACSCs) exceed an average of $14,000 per stay (Mkanta et al., 2025). With this, there is a need to change the current reactive model into a model that is more proactive and coordinated for residents with IDD to benefit from.

4. AS-IS Process Simulation

A simulation was developed in MATLAB to evaluate the potential impact of resident health monitoring on symptom progression and care costs for individuals with (IDD). The model simulates 1000 IDD patients for 365 days. The health state of each patient is tracked using a memory-based Markov chain. The evolution of the symptoms included in the model is described using a rules-based matrix which links symptoms to conditions and enables the determination of possible healthcare events such as doctor visits and hospitalizations. The model tracks the severity of the patient's symptoms, the diagnosed conditions, and the type of healthcare utilized during the simulation period to allow analysis of both average outcomes and extreme cases.

The simulation contains 73 observable symptoms derived from published literature on healthcare experiences among individuals with IDD. These symptoms represent the types of observations that may be made by DSPs during routine monitoring of residents. Each symptom is assigned a severity level and may occur independently or in combination with other symptoms. Symptoms are categorized into three severity levels: mild, moderate, or severe. These severity levels reflect the relative urgency and clinical risk associated with each symptom. The severity classification influences the likelihood that a symptom will escalate into a medical condition requiring clinical intervention. During each daily simulation step, patients may develop new symptoms or retain previously observed symptoms according to probabilistic transition rules defined within the Markov framework. The current state of the "AS-IS" system is highlighted in the simulation described below. The connection between improved symptom monitoring done by DSPs in the future with increased symptom detection is demonstrated. This is used to contrast the baseline (AI-IS) simulations with the improved future (TO-BE) simulations to see the impact of the improved monitoring and early detection of symptoms and health issues and how it reduces doctor and hospital visits.

4.1 Symptom to Condition Mapping

This algorithm converts symptom data into possible medical diagnoses. It utilizes a rules-based diagnostic matrix that maps symptom combinations to one of 50 possible medical diagnoses. The rules matrix consists of two primary rule types: single condition rules, where a single observed symptom is enough to suggest a possible condition, and multiple condition rules, where more than one symptom needs to be observed in order to suggest a possible condition.

4.2 Markov Chain Health State Progression

The dynamics of the symptoms and health states over time are modeled through a memory-based Markov chain process. Patients move from one state of symptoms to another on a daily basis with certain transition probabilities describing the occurrence of new symptoms, the resolution of current symptoms and the progression to more severe health states. The model has some persistence of state with some symptoms being active for more than one day. This is more in line with the reality of many medical conditions, where symptoms will be present and increasing if they are not treated. The daily transition process is used to decide the active symptoms for each patient at each time step, which are then used for symptom severity classification and condition diagnosis.

4.3 Severity State Model

At each time step, the health severity state of a patient is determined from the clinical condition determined from the set of active symptoms. The health states in the model are defined as: no symptoms, mild symptoms, moderate symptoms, and severe symptoms. The simulation tracks the number of days that each patient is in each of the severity states over the one year simulation period. The distribution of state-severity across all of the states of all of the individuals shows that most days are relatively mild, but a small number of days are moderately to very severely ill, and that a substantial minority of the individuals in the population experience a large number of moderately to very severely ill days. In a year of the length of a calendar year, there are on average 66,715 (18.28%) severe-symptom days among our patients.

4.4 Healthcare Utilization

Healthcare Utilization is modeled as a probabilistic outcome that depends on the reported levels of various symptoms and diagnosed health conditions. The model framework includes two types of healthcare events: doctor visits and hospitalizations. The average number of doctor visits per patient per year is 9.186. The number of doctor visits per patient is highly right skewed. This means that most patients have a few (moderate number) doctor visits per year, but a small percentage of the population visits the doctor a lot more often. The simulation gives an average of 1.417 hospitalizations per patient per year.

5. Performance Gap

The performance gap of the AS-IS Process Simulation is reduce the average of 9 doctor visits and 1.5 hospitalizations per patient per year to 3 and 0.5 respectively; the gap is 6 doctor visits and 1 hospitalization per patient per year.

6. Concept of Operations and TO-BE Process

The proposed system is a digital platform called CareAble used to transform IDD care from reactive healthcare management to one of proactive care. It is designed to improve early detection of medical issues for the IDD population living in assisted living facilities or group homes. The mobile application enables care staff to record daily health observations (symptoms and behaviors) of residents, which facilitates quicker discovery of new health changes and identification of emerging health issues. Ultimately, by providing a checklist of symptoms, mapping symptoms to conditions, and alerting of worsening symptoms and conditions to care staff, the platform supports earlier intervention leading to a reduction in preventable doctor visits and hospitalizations.

Checklist of Symptoms: CareAble provides a standardized checklist of 73 symptoms and behaviors that DSPs can use to document resident health observations during their day-to-day interactions with residents. The checklist includes monitoring for the "Fatal Five" conditions that are associated with the IDD population: aspiration, constipation, dehydration, seizures, and sepsis. These conditions often begin as minor symptoms that progress into more serious health issues if there is no intervention.

A Mapping of Symptoms to Conditions: Once the caregiver has recorded the resident's symptoms and submits the health log, the system then identifies possible underlying health problems that it may signal. The system internally uses a weighted scoring method to assess the severity of each symptom logged and maps to potential conditions it could be. This helps to identify potentially emerging, severe health patterns in residents.

Alerts for Snowballing Symptoms and Conditions: The application aggregates gathered resident data and identifies when symptoms are progressing into a more serious condition. Alerts are automatically generated and are displayed on a dashboard for DSPs to quickly identify which residents to monitor closely. This dashboard also displays more information on health trends, potential conditions, and recent observations, which enables the care team to quickly assess the resident's health and take the necessary action.

7. TO-BE Process Simulation

The baseline simulation represents the current practice (AS IS) and the TO-BE simulation is built on top of it to model the impact on patient health and healthcare utilization if the CareAble system is implemented. In the TO-BE state, DSPs are assumed to be using the CareAble app for monitoring and tracking patient symptoms. The TO-BE simulation is based on the same patient population, list of symptoms and condition model as the AS-IS simulation. The only difference between the scenarios is that symptoms are better identified and recorded in the TO-BE case, which increases the chance that less severe symptoms are diagnosed and treated before they progress into more severe symptoms of the condition. This intervention is represented by a higher rate of detection by DSPs of finding minor illness (mild or moderate symptoms) in the model. Detecting minor illness at an earlier stage in its progression means that it is identified before it has developed to the stage of severe illness which would require hospitalization.

7.1 Impact on the Number of Doctor Visits and Hospitalizations

The TO-BE simulation shows a reduction in doctor visits from 9.186 to 5.2 per patient per year. Hospitalizations decrease by 41.9% from 1.417 to 0.823 per patient per year. These results indicate that earlier symptom detection enables DSPs to intervene before conditions progress to a level requiring hospitalization.

7.2 Changes in Patient Severity States

In the TO-BE scenario, the average number of days per year spent in severe states decreases from 66,715 severe patient-days (18.28%) to 66,425 severe patient-days (18.20%). While the reduction appears small at the population level, the model reveals that the overall distribution of patient health states shifts significantly toward milder health states (i.e., more days are spent in less severe health states). This change suggests that early identification of symptoms in patients allows for more timely and less intense intervention by caregivers, thereby decreasing the clinical load of severe episodes.

7.3 Facility Cost Impact

The simulation also calculates the cost savings to the healthcare system resulting from the cuts. Compared to the baseline, the average annual cost per patient is expected to decrease by $39,664 (23.23%) across the TO-BE patient population. The savings come from fewer hospitalizations and severe clinical events, the most expensive part of care.

8. Implementation

The CareAble application is undergoing development in Python. The main end-users of the product are the DSPs who work in assisted living facilities or group homes. The app provides a dashboard to grant DSPs an overview of assigned residents and their health status, with alerts being displayed at the bottom of the screen, which can be seen in Figure 10. Figure 11 displays the standardized health form DSPs use to input symptoms and behaviors they observe in the residents they care for throughout the day. Multiple symptoms can be selected in one submission and multiple submissions are allowed. The "Fatal Five" conditions are in red as they are commonly associated with the IDD population. If there any additional notes that the DSP would like to expand on, there is a text entry box. Figure 12 shows the resident health predictions the tool outputs using machine learning algorithms that are based off resident health data inputted into the system; care recommendations such as monitoring strategies are provided to assist the care team in identifying potential health concerns before they progress into serious conditions and in making more informed decisions. Below are a few screenshots of the user interface from the perspective of a DSP.

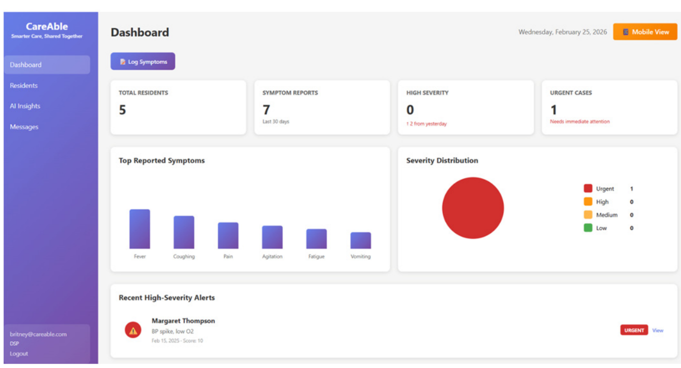

Figure 4. DSP Dashboard

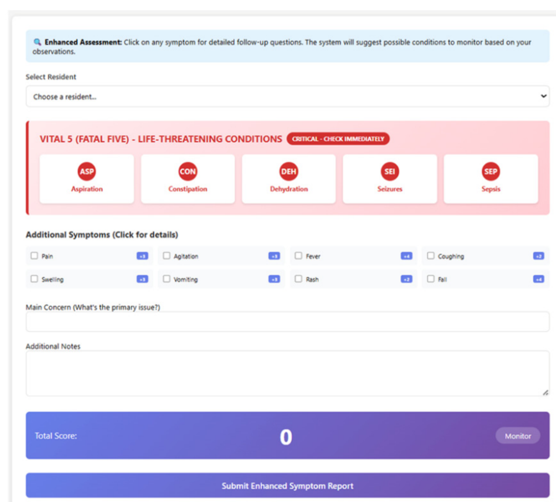

Figure 5. Resident Health Observation Log

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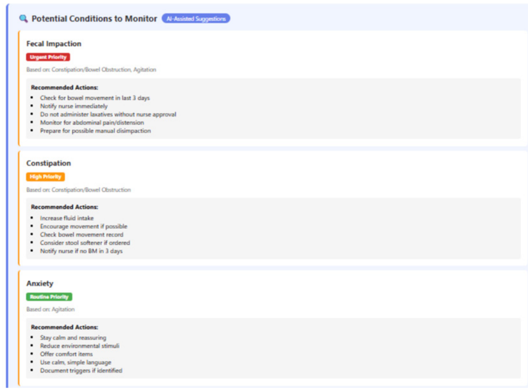

Figure 6. AI Insights for Potential Conditions to Monitor

9. Verification Test Results

A structured verification test plan was developed consisting of 84 individual test procedures organized into five major categories: (1) Symptom Observation Input, (2) Severity Classification, (3) Medication Administration Logging, (4) Data Storage and Audit Compliance, and (5) Resident Health Visualization. Each verification test was designed to validate a specific functional requirement under controlled conditions and confirm that the system behaved as intended. For example, the symptom-logging verification test ensured that DSPs could record resident health observations with all required fields completed, and that each entry was stored with a timestamp and user identifier. All tests were executed in a standard test environment using mobile devices and laptops, following detailed multi-step procedures to validate correct user interactions and expected system outputs. Currently 78 out of the 84 tests are passing. Once minor bugs are fixed, we expect for the remaining tests to pass.

10. Validation Test Results

A series of validation testing is to be conducted to help ensure CareAble may function as designed and meets the needs of all end-users. This was achieved through various validation scenarios and are outlined below. The validation testing consisted of four task-based evaluations aligned with the project's mission requirements. Each test involved representative end-users including DSPs, nurses, and facility managers performing real-world tasks using the system prototype. For example, one of the tests assesses whether DSPs can record at least 100 resident health observations daily. Together, all of these verification and validation tests provide a framework to ensure CareAble is both technically capable and may assist care teams.

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