



SOUTH DAKOTA ParentConnection

Resources for families of children with disabilities.

Background Information:

In 2012, South Dakota Parent Connection (SDPC) received a three-year grant from the Health Resources and Services Administration – Integrated Community Systems for Children and Youth with Special Health Care Needs (CYSHCN). Through the grant, SDPC brought together various agencies and organizations that serve/support families of CYSHCN. The SDPC Connection Community of Care Consortium (COCC) was developed and includes state government officials, nonprofit and advocacy organizations, health providers, and educators and was led by SDPC. This group explored how to enhance person-centered care and services coordination for families of children with disabilities and complex medical conditions. It began working on a roadmap that would include enhanced care coordination via document sharing, real-time care monitoring, navigation, and support to ensure positive outcomes for families and their children.

In October of 2015, through the efforts of the COCC, a potential system for meeting the needs of families of CYSHCN was identified. SDPC via the COCC began collaborating with Senscio Systems, Inc. of Boxborough, MA to bring up to 50 families of children with disabilities to a one-year pilot project. The project goal was to assess the effectiveness of document sharing, care navigation and coaching, and collecting and monitoring medical and activity data to support the daily management and coordination of care and services for the participating families.

Pilot Description:

Through the Family Empowerment through Technology (FET) pilot, SDPC, in concert with Senscio Systems, Inc created and tested a file sharing and permission system in which the parent serves as their child's "CEO" and ensures that the right information is shared with the right people at the right time during the child's and family's life journey. Parents and families were provided with a virtual document repository that allows parents to create permissions and share documents with their child's team. Parents were also provided with the Senscio Ibis Care Station to support activities of daily living prompts, reminders, medication guidance, and monitoring of family psychosocial well-being. The goal of the pilot was to onboard 50 families by the end of 2015 and continue for a one-year pilot period.

Selection Process: A descending seven-element criterion was identified for use in the selection process to enter people into the pilot project. Family Support Coordinators serving families covered by the HCBS Waiver – Support 360 program, were actively engaged in contributing to the selection of families. The goal was for 10 families to enter the pilot every two weeks over a 10-week period. The following selection criteria was developed:

1. First priority for selection of participants were to come from the HCBS Waiver 360 Program.
2. Within the Community Support 360 population, preferences were to be given to children between the ages of 10 and 20 years.
3. Focused selection was to include five geographic population hubs.

4. Focused selection was to be made to participants with current access to technology (high speed broadband).
5. Focus was also to include selection of families who demonstrate openness to the use of technology and capacity to commit to the project for the one year period.
6. Selection of families served by HSBS Waiver Support Coordinators with interest in engaging with families and the R/D project.
7. Goal of 50 total families. In the event the total number could not be achieved with FS360, selection of families covered under Choices HSBS Waiver could occur.

Family Responsibilities:

- Commit to a one year pilot
- Provide a dedicated space for the Ibis Care Station
- Sign forms (confidentiality, medical, use etc.)
- Use system daily
- Work with SDPC and Sencio staff to set up Ibis Care Station and document repository
- Provide feedback throughout the pilot

SDPC Responsibilities:

- Assist with enrollment
- Assist with set up of Ibis Care Station
- Provide guidance in setting up and using document repository
- Set up contact schedule with pilot families
- Maintain regular contact with family during the pilot process

Sencio Responsibilities:

- Set up Ibis Care Station system
- Coordinate with SDPC team to assist families in completing the forms
- Provide technical assistance and trouble shoot equipment
- Maintain regular contact with family
- Monitor Ibis Care Station daily

Pilot Phases:

Phase one (1): design and develop a Technology Application based on the SDPC's "MyFile" model:

1. Work will commence June 1, 2015
2. The period of performance is anticipated to be 90 days from project start, on or about August 31, 2015.
3. Deliverable will be a functional design ready for testing with a core group of consumer families upon phase 1 completion.

Creation of the repository was completed. However, Super Users (SDPC staff) attempted to use it but ran into technical issues that continued to be addressed. Therefore, the repository was not introduced to families outside the SDPC staff Super Users.

Phase two (2): deployment of a minimum of 30 *Ibis Care* systems across a representative group of volunteer families for a 12-month period.

1. Deployments will commence at a time mutually agreed to by SDPC and Senscio Systems.
2. Deployment of all systems will be completed by December 31, 2015.
3. Deliverables will include leased hardware and software to support the pilot deployments.
4. Care coordination will be provided by SDPC.

This phase was partially completed. The highest number of units placed at one time was 21. Eventually, several families withdrew from the pilot. At the end of the pilot program only 14 systems were with families, some of which were not being used or not used consistently.

HCBS Waiver funding was established, providing fiscal support for families in the form of payment of the \$85.00 monthly fee.

Strengths:

- Strong working relationship between Senscio and SDPC, most specifically evolving once Tony Burke came on board on behalf of Senscio.
- SDPC staff have become very knowledgeable about the system, its potential, and family needs and concerns.
- Positive relationship between families and SDPC. SDPC staff have been very responsive to family concerns. They have documented progress and on-going concerns, communicated concerns to Senscio in a timely manner and have conducted monthly follow-up visits with families.
- Strong advocacy by Family 360 Services Coordinators for families they serve.
- Strong support by Division of Developmental Disabilities through John Neu.
- Families have provided good feedback about the system both in concerns around use and what potential they see the system having if modifications (i.e. mobile platform) were achieved.
- SDPC has provided continued opportunity for Senscio to work with stakeholders at the State and local level, making introductions and client procurement for the system.
- Families for whom the system is working well for them have communicated that their child is attaining better independence through use of the daily routine feature.
- The system has a lot of features that, if they were modified to meet the needs of the DD population, show promise in promoting independence for individuals using it.

Needs:

Updated programming on the Care Station:

1. Pictures to be applicable to the person using it (google pics, Boardmaker, etc)
2. Accessibility for someone who is Deaf or Blind
3. Improvement in response time to concerns from families about tech issues
4. Notification when updates are occurring

Updated programming in the portal:

1. Activities and exercises- allow families to personalize instead of the current drop down feature since it doesn't offer all the options applicable to the individual
2. Appointments- allowing families to enter information about time, with whom, what the appointment is for
3. Taking away "early morning", "late afternoon", features and allowing families to enter specific times of the day that fit their child's school/work routines.
4. Mobile access is essential and needs to be a priority
5. ADLs- allowing for specific times instead of 30 minute increments
6. Ability to log and track seizures
7. ADL- allowing for an 'other' category and families to enter what that is (ex: piano lessons, clipping nails, cook dinner, etc.)
8. Parent/individual friendly- less tabs

Care station

1. Big and bulky
2. Buttons can be hard to push
3. Allow for more personalization/individualization
4. Other products have been identified (i.e. the Gizmo watch) that appear to be outpacing the Ibis Care Station in meeting the needs for a streamlined, user friendly, mobile device used to independently navigate a daily schedule. Two of the Super User families and one family who has previously tried the Ibis have purchased the Gizmo with the help of Family Support 360 dollars. The device has an initial cost that is 45% less than the purchase of an Ibis Care Station (\$135.00 vs \$300.00) and the monthly user fee cost 94% less (\$5.00 vs \$85.00).

Recommendations and Follow-up:

In late January and early February SDPC and Senscio spent considerable time discussing the strengths and needs as outlined above, keeping in mind the input given by the families. The original scope of the project was to provide a repository for families for ease of sharing important information about their family member with multiple stakeholders. The repository feature continues to have technical challenges. The daily scheduling feature of the care station, while having the potential to possibly provide a good deal of analytics, does not appear flexible enough for the individualization or customizability needed by those users in the developmental disabilities community. It was mutually agreed that the pilot program would end as of March 31, 2017. SDPC staff and Tony Burke have spent the last part of February and March personally visiting with each family in the pilot, arranging for and picking up care stations. Families have expressed appreciation for participation in the pilot and that their input was valued. Most indicated an interest in helping if needed for another pilot in the future.

Submitted by Carla Miller, Executive Director, SD Parent Connection