

# North Dakota Integrated Services Technical Report

Replicating Healthy Transitions Pilot Sites

**NORTH DAKOTA CENTER FOR PERSONS WITH DISABILITIES – MINOT STATE UNIVERSITY**

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North Dakota Integrated Services Project

# **North Dakota Integrated Services Technical Report**

## **Replicating Healthy Transitions Pilot Sites**

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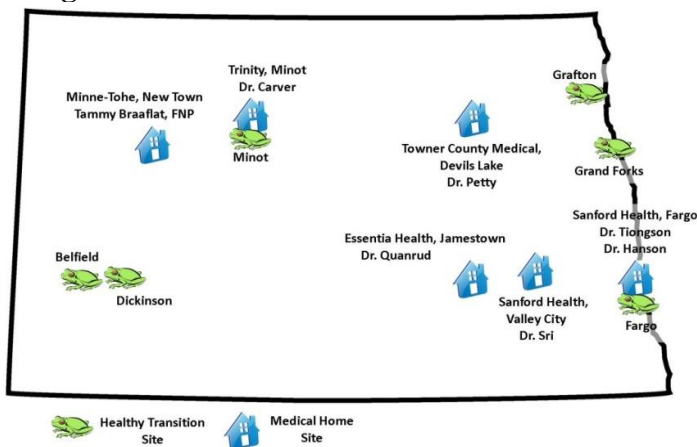


## Introduction

In 2008, the North Dakota Center for Persons with Disabilities, a University Center of Excellence on Developmental Disabilities at Minot State University, was a recipient of the State Implementation Grant from the Maternal and Child Health Bureau. Through this funding, the North Dakota Integrated Services (NDIS) project was developed and implemented from June 2008 through May 2011. The purpose of the NDIS project was to assist state agencies, local medical providers, and families of children and youth with special health care needs (CYSHCN) to develop the knowledge and infrastructure to assure that all youth receive coordinated health care in accordance with the American Academy of Pediatrics' definition of a medical home.

In order to achieve the goals set forth by the NDIS project, thirteen pilot sites were established in communities throughout North Dakota (ND). The sites were sought to encompass two elements of interest for improvement to NDIS staff: Medical Home practices and Health Transitions families. The resulting pilot sites consisted of seven Medical Home teams comprised of a primary care provider, a care coordinator, and a parent of a CYSHCN, and six Healthy Transitions families comprised of a CYSHCN and their family (see Figure 1). The Healthy Transitions families were tasked to use a team-based model to enhance healthy transitions for

**Figure 1**



CYSHCN in ND and implement transition strategies as deemed appropriate for individual CYSHCN. The purpose of technical report is to 1) provide a guide for the replication of Healthy Transitions pilot sites; 2) explore the impact made by Healthy Transitions pilot sites and NDIS

staff; and 3) provide recommendations for groups interested in replicating Healthy Transitions pilot sites.

### **Healthy Transitions Pilot Sites**

*Recruitment.* NDIS staff initiated the process of establishing Healthy Transitions pilot sites by first recruiting potential families. A recruitment letter (see Attachment A) was drafted by NDIS staff and sent to the Assistant Director of Special Education for the ND Department of Public Instruction to be disseminated to all of the Special Education Directors in ND. The directors then distributed the recruitment letter to Special Education teachers in their units. Recruitment efforts were geared in a way to garner participation from a range of ages of CYSHCN. If the Special Education teachers were able to identify any CYSHCN and their families who were interested in participating as a pilot family, they encouraged the families to contact NDIS staff.

Once a line of communication was established between individual families and NDIS staff, pilot families agreed to the stipulations of the project. These stipulations included: 1) Sharing health transition needs of the child with NDIS staff, including diagnosis; 2) Working as a team with medical professionals, educational professionals, and the family to implement strategies; 3) Collecting data; 4) Meeting at least one time monthly with NDIS staff (e.g., face-to-face or via distance technology); and 5) Possible travel to learning collaborative meetings. Each of these stipulations was critical to implementing a successful pilot test. The stipulations and their justifications are described below.

*Sharing health transition needs of the child with NDIS staff, including diagnosis.* It was imperative to the success of the pilot families that the diagnosis of the CYSHCN and their transition needs were well-documented. NDIS staff then used this information to connect the

pilot families with the most appropriate resources and strategies for their particular situation. NDIS staff also encouraged the participating CYSHCN to increase their knowledge of their medical history and condition in order to become advocates for their needs. This led to the adoption and modification of the NDIS Advocacy Folders, which were meant to increase the self-awareness of the CYSHCN as well as to be a tool to ease transition phases.

The NDIS Advocacy Folders were adopted and modified from a tool that was used by students at the Anne Carlsen Center. This tool consisted of an accordion folder that was tabbed in order to help CYSHCN organize any pertinent documents they may acquire. The tabbed sections are labeled: *Personal Information* (Birth Certificates, Social Security Card, Personal Care Needs, etc.), *Medical Information* (Diagnostic Documentation and Medical History, Recent Care Plans, Family History, etc.), *Money Management Information* (Student Loan Information, Credit Card Statements, Bank Contact Information, etc.), *Education Information* (Copies of IEPs, Educational Testing Reports, Class Schedules, etc.), *Advanced Directives* (Power of Attorney, Living Will), and *Career Information* (Vocational Assessment Reports, Employment Background, Letters of Recommendation, etc.). The Advocacy Folders were meant to be personalized to meet the needs of the particular CYSHCN, whether they are transitioning from pediatric care to adult care, elementary school to middle school, or high school to postsecondary life. For a sample copy of this folder, please contact Megan Laudenschlager (1.800.233.1737 ext. 3423, [megan.laudenschlager@minotstateu.edu](mailto:megan.laudenschlager@minotstateu.edu)) or visit the NDIS website at [www.ndcpd.org/ndis](http://www.ndcpd.org/ndis) to download the tools used to create this folder.

*Working as a team with medical professionals, educational professionals, and the family to implement strategies.* The American Academy of Pediatrics defines the Medical Home model as care that is: “is accessible, continuous, comprehensive, family-centered, coordinated,

compassionate, and culturally effective”. NDIS staff felt that this same concept should be applied to the realm of transitioning throughout the lifespan; therefore, NDIS staff aided pilot families in communicating with all of the stakeholders in their CYSHCN’s care in order to achieve the best outcomes.

NDIS staff recognized that oftentimes families of CYSHCN end up having to tell and re-tell their situations to multiple agencies multiple times; therefore, NDIS staff drafted an Interagency Agenda (see Appendix B). The Interagency Agenda is a meeting method developed for agencies and providers that is aimed to increase the level of communication and collaboration between the different stakeholders of expertise (doctors, therapists, etc.) to generate a more coordinated transition for the CYSHCN. In order to successfully implement this method, it is imperative that all of the stakeholders be present at the meeting either face-to-face, via distance technology, or by conference call. The Interagency Agenda also called for the CYSHCN to be the facilitator of the meeting, which would build their capacity in self-advocacy.

When introduced to and piloted by participants of the project and individuals at the state level, the Interagency Agenda method was well-received; however, some thought that this method would be difficult to implement regularly or on a wide scale due to the busy schedules of agency personnel, parents, and care providers. Regardless, all thought that the Interagency Agenda method was a standard to be strived for by all stakeholders caring for and families of CYSHCN. For a sample copy of the Interagency Agenda, please contact Megan Laudenschlager (1.800.233.1737 ext. 3423, [megan.laudenschlager@minotstateu.edu](mailto:megan.laudenschlager@minotstateu.edu)) or visit the NDIS website at [www.ndcpd.org/ndis](http://www.ndcpd.org/ndis) to download the tool.

*Collecting data.* In order to determine whether identified transition strategies were leading to positive effects on the participating CYSHCN and their families, NDIS staff adopted

Plan-Do-Study-Act (PDSA) cycles in order to evaluate small tests of change with each family. Each family was instructed on how to deconstruct long-term goals into short-term goals; track their progress with individual PDSA cycles; and to evaluate whether the small, everyday life changes they implemented to reach their goals were successful (see Appendices C and D). Some goal areas addressed by Healthy Transitions families with PDSA cycles include:

- Independently managing health issues
- Decreasing anxiety of transition from middle school to high school
- Developing independent livings skills
- Transitioning to adult roles
- Medication management/independence
- Organization of personal belongings
- Building self-advocacy skills
- Increasing access to social interaction

All families found success with PDSA cycles and observed significant improvement in their progress toward their goals; however, mixed feelings existed toward the user-friendliness and measurability of the results of the PDSA cycles. Families found it difficult to measure behaviors adequately and without bias, keep a data log, and interpret the results of each cycle. In addition, many families thought that continuing the use of PDSA cycles would be difficult, if not impossible, without the technical assistance provided by NDIS staff.

*Meeting at least one time monthly with NDIS staff.* Healthy Transitions pilot families were encouraged to meet with NDIS staff either face-to-face, via distance technology, or through conference calls in order to evaluate PDSA cycle progress as well as to address any new

developments in the transition needs of the CYSHCN. NDIS staff believed that frequent contact would ensure engagement in the project and its activities by the pilot families.

*Possible travel to learning collaborative meetings.* Healthy Transitions pilot families were asked to be a part of a network of learning collaborative meetings that the NDIS project developed, implemented, supported, and evaluated. Topic specific learning collaborative meetings were established for medical home, family involvement/cultural competence, and healthy transitions to work. The intent of the collaborative meetings was to provide training to increase knowledge, awareness, and competence in implementing integrated health care practices, and provide training to increase cultural competence, including responsiveness to unique family needs and diverse families, policy makers, and health care and support service providers.

The NDIS project conducted nine successful learning collaborative meetings, all with a specific theme. Themes included “Medical Home”, “Outcomes for CYSHCN”, “Coding + Family Involvement”, “Care Coordination”, “State and Local Resources”, “What We’ve Learned”, “Healthy Transitions”, “Early and Continuous Screenings”, and “Sustainability”. Through these collaborative meetings, Healthy Transitions pilot families were given the opportunity to network and share their personal stories with medical home providers and agency personnel. The NDIS project provided travel supports for mileage and per diem to participants attending learning collaborative meetings to support their involvement.

## **Impact**

Because of the vast array of agency relationships that were established and strengthened by NDIS staff, the issues surrounding transitioning CYSHCN have been given considerable focus at the state level. The Healthy Transitions Community of Practice (CoP) subcommittee

was established in ND by the State Transition CoP through the Department of Public Instruction in partnership with the NDIS project. In addition, an offer was extended by the State Transition CoP to an NDIS Healthy Transitions youth and parent to join the CoP State Advisory Committee and the Youth Leadership subcommittee. Through these positions, the youth will provide self-advocacy and self-awareness training, as well as participate in leadership opportunities across the state. Through these developments, the NDIS project and Healthy Transitions pilot families have made a positive impact in the state regarding the issues surrounding transition for all children and youth, not just those with special health care needs.

### **Recommendations**

Throughout the creation and implementation of both the Medical Home and Healthy Transitions pilot sites, NDIS staff had difficulty keeping the two elements from becoming disjointed although the two are highly related and build upon each other. As a result, NDIS staff had two classifications of sites that were receiving separate and slightly inadequate elements of the comprehensive medical home model of care. In order to remedy this issue, NDIS staff recommend that Medical Home and Healthy Transitions pilot sites not be mutually exclusive; the same CYSHCN who are being provided with a medical home should be provided with transition assistance.

Although the network of learning collaborative meetings worked extremely well for assisting in Medical Home and Healthy Transition pilot site education, network relationships, and technical assistance, not all learning collaborative meetings were able to be accessed by all NDIS participants. Many meetings were held during the week, which created difficulty by upsetting the routines of CYSHCN, needing to arrange childcare, and being granted time off of work. In addition, many pilot participants simply did not want to travel over nearly one hundred

and fifty miles to attend a learning collaborative meeting. NDIS staff recommend that any group attempting to replicate a network of learning collaborative meetings ensure that the meetings are accessible for individuals who cannot find the time to travel by offering the ability to attend via distance technology.

## Appendix A

To:  
From: NDIS Project Coordinator  
Re: Recruitment for Healthy Transitions Pilot Teams  
Date: January 27, 2010

The North Dakota Integrated Services project is looking for teams to participate in a pilot project to implement strategies that assist in facilitating healthy transitions from school age to adulthood for children and youth with special health care needs. Qualifications for participation include having a diagnosis as a child or youth with special health care needs. Ages sought include 5-11 (elementary age); 12-13 (junior high); 14-18 (grades 9-12); 18-21 (grade 12+); and 21-26. The child or youth may or may not be on an IEP through the school. In fact, a mix of both is preferred across all participants.

### Project Objective:

Use a team based model to enhance healthy transitions for children and youth with special health care needs in ND. Pilot test strategies that are appropriate for the child/youth, family, and the team. Participants will:

- 1) Share health transition needs of the child with the team, including diagnosis.
- 2) Work as a team with medical professionals, educational professionals, and the family to implement strategies.
- 3) Collect data.
- 4) Meet at least 1 time monthly with NDIS staff (e.g., face to face or via distance technology).
- 5) Possible travel. Travel will be reimbursed. Due to the nature of the child or youth with special health care needs, creative solutions may be available to meet the family's travel needs. Some options if not able to travel might include using technology such as Skype, webinar format, video record information to share with the team, etc.

## Appendix B



## Interagency Agenda

Developed for agencies and providers serving  
Children and youth with special health care needs

\*Facilitator is responsible for addressing all relevant aspects of the agenda outlined

Agenda item	Person(s) responsible	Timeline
1. <i>Introductions and purpose of the meeting</i>	<i>Facilitator</i>	
2. <i>Review necessary demographic information and update contact information as needed</i>	<i>All</i>	
3. <i>Tell the story (Youth's perspective is preferred)</i>	<i>All</i>	
<b>Goals</b>	(Facilitator)	
<ul style="list-style-type: none"> <li>• Goals for the future               <ul style="list-style-type: none"> <li>○ Short term</li> <li>○ Intermediate</li> <li>○ Long term</li> </ul> </li> </ul>		
<b>Past</b>	(Facilitator)	
<ul style="list-style-type: none"> <li>• Medical issues</li> <li>• Diagnoses</li> <li>• Assessments (results, procedures, relevant information)</li> <li>• Social and interpersonal issues</li> </ul>		
<b>Present</b>	(Facilitator)	
<ul style="list-style-type: none"> <li>• Present level of academic and functional performance</li> <li>• Current social and interpersonal issues</li> <li>• Manifestation of diagnoses and treatment in all settings</li> </ul>		
<b>Future</b>	(Facilitator)	
<ul style="list-style-type: none"> <li>• Activities to reach the goals identified above               <ul style="list-style-type: none"> <li>○ Short term</li> <li>○ Intermediate</li> <li>○ Long term</li> </ul> </li> <li>• Plan development (Each agency identify needs for written plan)</li> <li>• Manifestation of diagnoses and treatment in all settings               <ul style="list-style-type: none"> <li>○ Supports needed (accommodations)</li> <li>○ Changes suggested for the environment (modifications)</li> <li>○ Services needed (related services, referrals, treatments)</li> </ul> </li> </ul>		
4. <i>Symptoms, suggested tests, recommendations, intervention plans, things to avoid</i>	<i>(Facilitator)</i>	
5. <i>Supports needed</i>	<i>(Facilitator)</i>	
Item/service	Responsible party	Timeline
Equipment:		
Assistive technology:		
Accommodations:		
Modifications:		
Special needs or requests:		
Other (please explain):		
6. <i>Additional information needed</i>	<i>(Facilitator)</i>	
7. <i>Next meeting</i>	<i>(Facilitator)</i>	
8. <i>Adjourn</i>	<i>(Facilitator)</i>	



## Summary of PDSA Cycles NDIS Learning Collaborative

A **PDSA (Plan-Do-Study-Act)** cycle is a way of determining if a change leads to improvement.

Why should we test these changes?

- To decide which of several proposed changes will lead to the desired improvement or goal
- To evaluate how much improvement can be expected from the change
- To decide whether the proposed change will work in the your life
- To evaluate the results from a proposed change
- To lower resistance upon the use of the proposed change because you have evidence that the change works.

### **Step 1-Plan**

Plan the test or observation, including a plan for collecting data.

1. State the objectives
2. Make predictions (what will happen and why)
3. Develop a plan to test (who, what, when, where, and what data needs to be collected)

### **Step 2-Do**

Try out the test on a small scale.

- Carry out the test
- Document problems and unexpected results

### **Step 3-Study**

Set aside time to examine the data and study the results.

- Complete the analysis of data
- Compare the data to your predictions
- Summarize and reflect on what was learned

### **Step 4-Act**

1. Refine the change based on what was learned from the test  
Determine what changes should be made (what worked, what did not, what should be kept/abandoned)
2. Prepare a plan for the next test

\*In this last phase, you will decide if there are any adjustments needed to the change you have tried. This may lead to additional test cycles, which starts the process all over again with a plan!

Appendix D

**PDSA Worksheet**  
**Plan-Do-Study-Act**

**Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**PURPOSE/OBJECTIVE OF CYCLE:**

**PLAN:** *the change, predictions, and data collection*

**The Change**

- What are we testing?
- Who are we testing the change on?
- When are we testing?
- Where are we testing?

**Predictions**

- What do we expect to happen?

**Data**

- What data do we need to collect?
- Who will collect the data?
- When will the data be collected?
- Where will the data be collected?

**DO:** *Carry out the change/test; collect data and begin analysis*

- What was actually tested?
- What happened?
- Observations
- Problems

**STUDY:** *Complete analysis of data, summarize what was learned, and compare the data to predictions*

**ACT:**

- What changes should be made before the next test cycle?
- What will the next test cycle be?
- Are we ready to implement the change?