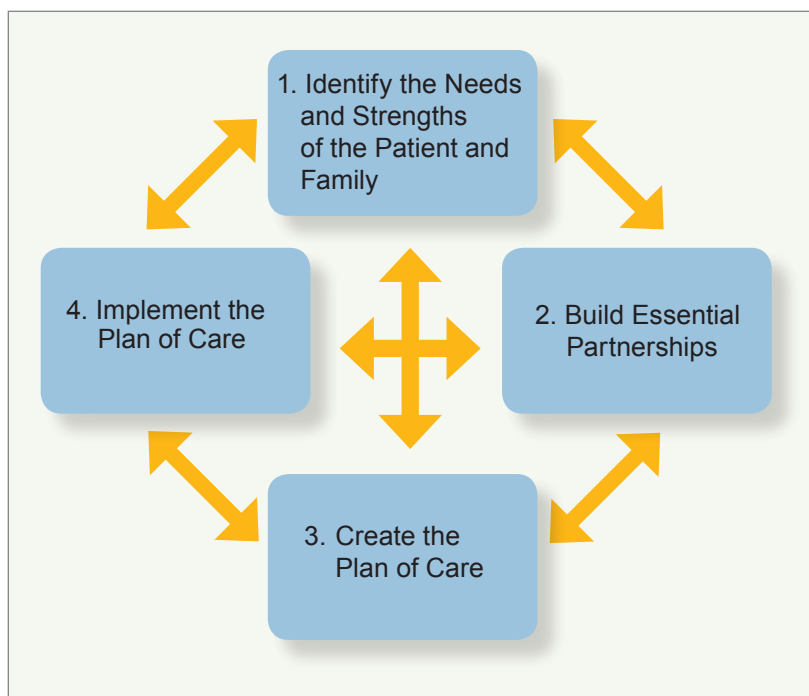


Report

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs



Jeanne W. McAllister, BSN, MS, MHA

Acknowledgments

Lead Author: Jeanne W. McAllister, BSN, MS, MHA

ABOUT THE AUTHOR: Jeanne McAllister is an Associate Research Professor of Pediatrics at Indiana University School of Medicine, Children's Health Services Research Division. As Co-Founder and former Director of New Hampshire's Center for Medical Home Improvement (CMHI; 1997-2013) Ms. McAllister brings over thirty years of health care experience to the arena of health care improvement, education, and research.

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs is a product of the teamwork among the devoted individuals listed below. Many ideas, strategies and suggestions in this companion Implementation Guide originated with this team. Their commitment to improving care, and doing so in partnership with their health care improvement counterparts is a positive example of collaboration for innovation.

Plan of Care Development Team

Carolyn Allshouse, Director, Minnesota Family Voices
Elizabeth Collins, BSN, MSN, Director, NH Title V Director
Sarah Larson, LPN, Care Coordinator at CentraCare, MN
Patricia Lucarelli, MSN, RN-BS, CPNP, APN, NAPNAP Representative
Peggy Mann Rinehart, Family Consultant
Jeanne W. McAllister, BSN, MS, MHA, Principal Investigator
Marinell Newton, MSW, VT Title V Care Coordinator
Marilyn Peitso, MD, Pediatrician, CentraCare, MN
Jill Rinehart, MD, Pediatrician, Hagan, Rinehart and Connolly, PLLC, VT
Susan Smiga, MD, Child Psychiatrist, Geisel Medical School at Dartmouth

Center for Medical Home Improvement Staff

Lori Keehl-Markowitz, BSN
Leah Reed

As a development team we thank our group of skilled advisors whose sage advice shaped how we have presented our collective thinking. These advisors include:

Beverly Baker, National Family Voices
W. Carl Cooley, MD, Crotched Mountain Foundation, AAP/Medical Home Advisory
Denise D Dougherty, PhD, AHRQ
Michelle Esquivel, MPH, AAP, Division for Children with Special Needs
William Kassler, MD, PhD, Medical Director, CMS New England Regional Office
Dennis Kuo, MD, AAP/Council on Children with Disabilities
Linda Lindeke, PhD, APRN, NAPNAP
Doris Lotz, MD, NH Medicaid Medical Director
Marie Mann, MD, Project Officer, USMCHB, Division of Services for Children
with Special Health Care Needs
Andrew Racine, MD, AAP, Council on Children's Health and Finance
Lee Sanders, MD, Stanford University, Information Technology
Julie Schilz, BSN, MBA, Wellpoint
Sarah Hudson Scholle, DrPH, Vice President, NCQA
Edward L. Schor, MD, Lucile Packard Foundation for Children's Health
Geoffrey R. Simon, MD, AAP Committee on Practice & Ambulatory Medicine (COPAM))

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. The Foundation is a public charity, founded in 1997.

Table of Contents

Introduction 2

Background 2

 Principles for Successful Use of a Shared Plan of Care 3

The Plan of Care Model: Family Centered, Comprehensive, Integrated 4

 Recognize Needs and Strengths of Patient and Family 4

 Build Essential Partnerships 4

 Construct Plan of Care 4

 Implement Plan of Care 5

A Step-By-Step Approach to the Shared Plan of Care 6

 Ten Steps Toward Implementation: Index 7

Conclusion 8

References 9

Major Components of a Shared Plan of Care10

Find this report on line at: <http://lpfch-cshcn.org/publications/research-reports/achieving-a-shared-plan-of-care-with-children-and-youth-with-special-health-care-needs>



400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301 (650) 497-8365
www.lpfch.org

Introduction

Identifying, accessing and coordinating services that benefit an individual child or youth with special health care needs is a difficult but necessary part of good quality health care. Providing such care requires a continuous collaborative effort by children/youth, families, and their care team. The best means of guiding and documenting these efforts is an individualized and comprehensive plan of care.

A plan of care includes the information necessary to assure that issues affecting a child's health and health care are identified, and that activities and accountability for addressing them are documented. The best strategies, care structures, processes and outcomes result when patients, families and health care providers form trusting, caring partnerships and draw upon one another's perspectives and expertise.

In this report, the recommended core content of a comprehensive and integrated plan of care is outlined, as are the steps necessary to create and share a plan of care. *Achieving a Shared Plan of Care: An Implementation Guide* and related materials are offered separately to help families, clinicians and community partners improve care and assure quality for children with chronic or complex health care needs.

Background

Care plans have been consistently recommended as part of the care of individuals with chronic health problems for many years. Sometimes care plans are limited to specific settings such as hospitals, or they are used for time-limited care around a specific episode of illness. More recently, care plans have been identified as an essential element of a medical home for children with special health care needs. When appropriately developed in partnership with patients and families, a single, comprehensive, integrated and shared plan of care strengthens relationships, enhances communication, and improves outcomes.¹⁻⁵ Despite their inherent value and conceptual support, there is no consensus on either the content of care plans or the process of care planning. Only a limited number of articles in the professional literature offer specific guidance as to the dimensions or core components of a plan of care.^{1,6,7}

Despite their inherent value, there is no consensus on either the content of care plans or the process of care planning.

In 2012, with support from the Lucile Packard Foundation for Children's Health, a development team (composed of families, clinicians, care coordinators and policymakers) and then an expert national advisory committee were convened to develop standards for comprehensive, integrated care plans and care planning. The intention was that plans of care would be developed for each child with special health care needs, and that such plans would be maintained and used over their life course.

The work began with agreement on core principles necessary for the successful creation and use of a shared plan of care. The principles are predicated upon the expectation that care for children with special health care needs will occur within a family-centered medical home characterized by team-based care. The principles are both conceptual and pragmatic; they address participation in the development and use of the plan of care by patients, families and providers.

Principles for Successful Use of a Shared Plan of Care

1. Children, youth and families are actively engaged in their care.
2. Communication with and among their medical home team is clear, frequent and timely.
3. Providers/team members base their patient and family assessments on a full understanding of child, youth and family needs, strengths, history, and preferences.
4. Youth, families, health care providers, and their community partners have strong relationships characterized by mutual trust and respect.
5. Family-centered care teams can access the information they need to make shared, informed decisions.
6. Family-centered care teams use a selected plan of care characterized by shared goals and negotiated actions; all partners understand the care planning process, their individual responsibilities, and related accountabilities.
7. The team monitors progress against goals, provides feedback and adjusts the plan of care on an ongoing basis to ensure that it is effectively implemented.
8. Team members anticipate, prepare and plan for all transitions (e.g. early intervention to school; hospital to home; pediatric to adult care).
9. The plan of care is systematized as a common, shared document; it is used consistently by every provider within an organization and by acknowledged providers across organizations.
10. Care is subsequently well coordinated across all involved organizations/systems.

The Plan of Care Model: Family-Centered, Comprehensive and Integrated

Fundamentally, the plan of care is envisioned to be an assessment-based, goal-driven, comprehensive and dynamic document whose success rests on effective, ongoing communication and collaboration among all who are involved in a child's care. Because the plan of care is envisioned as a proactive, dynamic, and therefore changing document, it cannot be separated from the processes involved in its development and use. Use of the plan of care is expected to increase quality and efficiency and improve medical, social, functional, and financial outcomes. As designed, care plans also necessitate meaningful engagement of youth and families as partners in their health care.²

Figure 1 provides a visual representation of the ongoing, non-linear, dynamic processes involved in creating and using a plan of care.

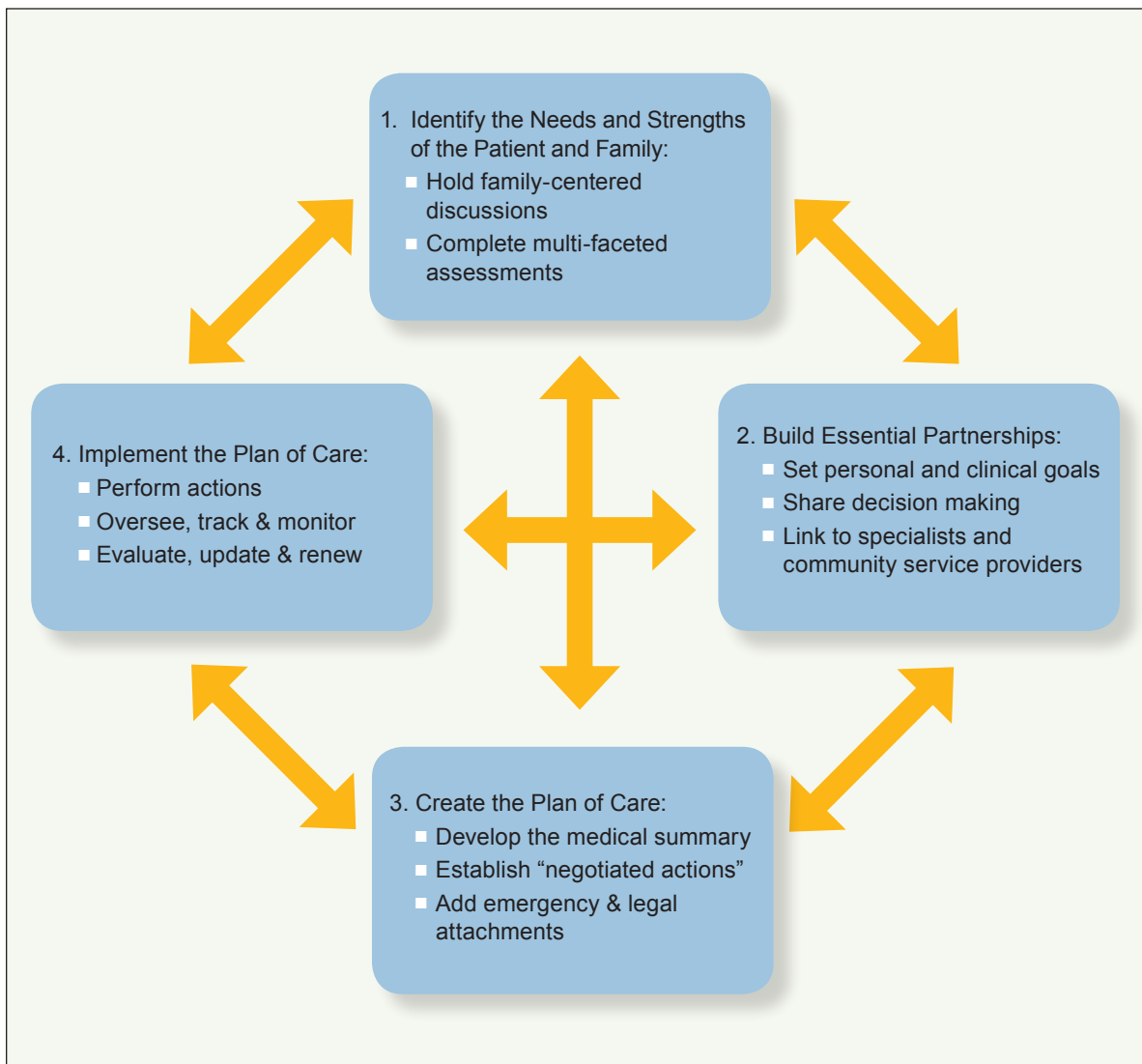
This figure depicts four key elements of the care planning process:

- **Identify the Needs and Strengths of the Patient and Family** The success of any care intervention ultimately depends upon actions taken by the patient and family, and so a plan of care must consider the family's circumstances and capacities. Health care providers, in particular, have a uniquely privileged opportunity to know and understand the family by virtue of forming a respectful and mutually trusting relationship. As a consequence, the health care team, in partnership with the family, is able to perform a comprehensive assessment of strengths, needs and gaps, and address interrelated medical, social, developmental, psychological, behavioral, educational, environmental and financial concerns.
- **Build Essential Partnerships** Effective partnerships rest on mutual interdependence in the pursuit of articulated, shared goals and outcomes. Agreeing on those goals and their underlying values allows the patient, family and providers to jointly guide care, and creates the opportunity to measure progress. Treatment and other intervention decisions thus can be made in partnership, drawing from patient and family preferences and best available evidence. Since care plans for children frequently require the contributions of additional community service providers, these partners need to be identified, brought into the care planning process, and encouraged to access and use the plan of care.
- **Create the Plan of Care** Assuring high quality coordination of a child's future care requires that a care plan be in place — it cannot be otherwise. Access to a concise summary of health care events, current needed treatments, ongoing issues, and stated goals are essential. Having a plan of care is particularly beneficial for those newly involved and therefore unfamiliar with the child, family and their circumstances. Determining, agreeing on, and accepting individual responsibility for strategies necessary to meet goals are challenging but necessary tasks. For children who have conditions that

are likely to worsen abruptly and require urgent care, a set of specific emergency actions should be attached to their plan of care. Other attachments may include rare condition fact sheets and legal documents outlining guardianship and decision-making privileges.

- **Implement the Plan of Care** A plan of care is only valuable as a living, changing document owned and implemented by all involved in the daily life of the child. For the medical home, the planning process needs to be incorporated as a routine part of the care of children with chronic or complex problems. At each visit progress toward clinical and personal goals (child/family) should be assessed. In the aggregate and over time, the success of a practice in documenting and achieving goals outlined in each plan of care can be used to gauge the quality of care being provided to the population of children with special health care needs.ⁱ

Figure 1: Shared Care-Planning Model Created in Partnership with Families



i. The accompanying Implementation Guide provides a set of measurement strategies to assist with evaluating the care provided within a medical home (<http://lpfch-cshcn.org/wp-content/uploads/2014/04/Achieving-a-Shared-Plan-of-Care-Implementation-Guide.pdf>).

A Step-By-Step Approach to the Shared Plan of Care

Ideally, all children should have a plan of care. For healthy and typically developing children the American Academy of Pediatrics recommendations for preventive pediatric health care, paired with the guidance provided by Bright Futures, is likely to be enough. However, for children with chronic or complex problems, having a more comprehensive and integrated plan of care is a prerequisite for high quality care. Although there can be substantial costs to the practice (and family) in creating a plan of care, some of these practice costs are billable using CPT codes 99487-99489 for complex chronic care coordination. For eligible adults, Medicare is expanding billing opportunities for required chronic-care management. Regulations require practices to develop a “patient-centered plan of care” document, which would typically include a “problem list,” expected outcomes, measurable treatment goals, symptom and medication management, and coordination of services delivered by specialists and social service providers.

Although there can be substantial costs to the practice (and family) in creating a plan of care, some of these practice costs are billable.

For children and youth with special health care needs, practices vary as to their capacity to develop and implement care plans. Planned, coordinated care becomes easier when practices engage in both their day-to-day work and their quality improvement efforts as a team. The inclusion of families, not only in planning their own child's care but also as improvement partners for the practice, benefits all and may enhance outcomes. Implementing care planning is best done in a stepwise fashion, identifying, testing and adopting new approaches and procedures. Workflow or work responsibilities are apt to change, so an organized approach to implementation will minimize disruptions. Having an idea of the intended results of care planning implementation is essential. Figure 2, Major Components of a Shared Care Plan, offers a recommended plan of care template. The following 10 Steps break down the testing and implementation process into a sequence of manageable activities.

Ten Steps Toward Implementation

Step 1. Identify who will benefit from having a care plan.

- Select criteria to identify the children and families who would benefit from having an accessible, comprehensive, integrated and shared plan of care.

Step 2. Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.

- Talk with the patient and family about the value of a shared plan of care and their central role in its dynamic development and use; share with them that other families have recommended this as a helpful strategy.
- Review with colleagues your understanding of the family perspective, including the importance of communication and collaboration; link the plan of care conceptually with better health care, population health and costs per capita.

Step 3. Select, use and review multi-faceted assessments with the child, youth and family.

- Use findings to frame child and family needs, strengths, resources, and circumstances.

Step 4. Set shared personal (child and family) and clinical goals.

- Work together to agree upon clinical goals of care, specific child and family goals, and their relative order of priority.

Step 5. Identify other needed partners and link them into the plan of care process — subspecialists, community resource providers and others.

- Clarify who the “lead team” is (locus of care coordination) for the family, other team members, and partners

Step 6. Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.

- For some children, an emergency plan of care, necessary legal documents, and additional rare condition fact sheets, or other specific guidance, should be attached.
- Merge with Negotiated Actions dimensions (Step 7).

Step 7. Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6.

- Negotiate accountability for each action.
- Ensure that anticipated transitions are addressed, including between school levels, hospital to home, and pediatric to adult-focused health care.

Step 8. Ensure that the plan of care is accessible, retrievable, and available.

- Make the plan of care available in real time for families and practice staff.
- Use it at each health care encounter and/or contact with the child and family.

Ten Steps Toward Implementation (cont.)

Step 9. Provide tracking, monitoring and oversight for the plan of care.

- Regularly review contents and progress with the family, modify data and goals as necessary, while updating actions and accountabilities.
- At least annually, or according to each individualized plan, reassess the circumstances of the child and family including their physical, mental, cognitive, social, functional and environmental health status, and determine the use of and need for additional resources and supports, similarly revising the plan.

Step 10. Systematically use the plan care model process as a life course and a population health approach.

To gain the greatest benefits from creating and implementing a plan of care, every “partner” (patient, family, medical home clinical team, and identified subspecialists, community and school providers) will need to be aware of, have access to, and be able to use the plan of care. While implementing care plans requires good processes and skilled people, good tools are also needed. As health information technology becomes universally adopted, care plans need to be electronically accessible, updateable, downloadable and transmittable.⁸ Together these essential elements all contribute to the achievement of a standardized and measurable approach to planned, coordinated and high quality, family-centered care.

Accomplishing many of these steps can be facilitated through the use of the “Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs: An Implementation Guide” and its explanatory examples and tools (<http://lpfch-cshcn.org/wp-content/uploads/2014/04/Achieving-a-Shared-Plan-of-Care-Implementation-Guide.pdf>).

Conclusion

The purpose of planned care is to achieve better, safer, more coordinated care resulting in optimal child and family outcomes. A core strategy is to solidify the relationship among children, families and their health care team through the creation and use of a plan of care with a longitudinal view. Communication, collaboration and co-management with sub-specialists and community partners supply needed integration and comprehension. The partnership relationship formed enables each child, youth and family to reflect upon what matters most to them and to have health care interventions and actions linked with their goals. This embodies the kind of patient and family-centered care that current literature shows to be associated with better outcomes.

References

1. Adams, S., et al., *Exploring the Usefulness of Comprehensive Care Plans for Children with Medical Complexity: A Qualitative Study*. BMC Pediatrics 2013. 13(10).
2. Carmen, K., et al., *Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies*. Health Affairs, 2013. 32(2): p. 223-231.
3. American Academy of Pediatrics Committee on Children with Disabilities, *Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children with Special Health Care Needs*. Pediatrics, 2005. 116(5): p. 1238-1244.
4. Antonelli, R., McAllister, J.W., and Popp, J., *Making Care Coordination a Critical Component of the Pediatric Health Care System: A Multidisciplinary Framework*. 2009, The Commonwealth Fund: New York, NY.
5. McAllister, J.W., et al., *Medical home transformation in pediatric primary care — what drives change?* Annals of Family Medicine, 2013. 11 Suppl 1: p. S90-8.
6. Mangione-Smith, R., et al., *Measuring the effectiveness of a collaborative for quality improvement in pediatric asthma care: does implementing the chronic care model improve processes and outcomes of care?* Ambulatory Pediatrics, 2005. 5(2): p. 75-82.
7. McDonald, K., et al., *Closing the Quality Gap: A Critical Analysis Of Quality Improvement Strategies*. 2007, Agency for Healthcare Research and Quality: Rockville MD.
8. Kellerman, A. and Jones, S., *What It Will Take To Achieve The As Yet Unfulfilled Promises of Health Information Technology*. Health Affairs, 2013. 32(1): p. 63-68.

Figure 2
Major Components of a Shared Care Plan

Part I Medical Summary

Describe the Child/Youth/Family

Name/Likes to be called:

- Sex
- DOB
- Race
- First language
- Emergency plan on record? (___ Yes/Link) (___ Not Needed)
- Diagnosis
- Problem list
- Short summary
- Mental status

Medical Home Neighborhood Mapping Contacts: (e.g. family support, health, school and community partners)	Role/Responsibilities	Best way to contact
1.		
2.		
3.		

Family structure — succinct social /educational summary; includes strengths

- Siblings (Ages, health/wellness concerns, functional ability, etc.)
- Cultural considerations/preferences
- The primary concern of the family (in their words)
- The family response to “What I/we want you to know about me/us”

Part II Medical Summary — Describe/list:

- The diagnoses
- Problem list
- Short narrative summary
- Mental status/level of consciousness
- Current interventions, treatments and therapies
- Other approaches tried and not tried
- Developmental concerns
- Environmental concerns
- Other_____

Part III “Negotiated Actions” (e.g. Strategies and plans to address each goal)

What are the family/child/youth’s identified goals (i.e., what matters to them)?

- Patient Goal(s) (dated)
- Family Goal(s) (dated)

Clinical treatment goals (best available evidence)

- Primary care clinician goal (dated)
- Sub-specialist(s) goal (dated)
- Community providers(s) goal (dated)

For each prioritized goal – identify actions/strategies, accountable persons (includes subspecialists and community partners), and a timeline for completing the actions:

Goal	Actions /Strategies	Accountable Person	Timeframe
Patient goal(s)			
Family goal(s)			
Clinical goal(s)			

Use and regularly update the plan of care

Evaluate the shared care process

- Are there methods in place for effective communication?
 - Type of communication (email, messaging, phone, face-to-face, cloud, etc.)
 - Persons communicating (family, cross-team, and community partner)
- Is the plan practical and feasible?
- Are resources obtainable?
- Are there any additional barriers?
- Are the activities adequate to facilitate use of the plan?
- Is there adequate documentation of actions?
- Is progress assessed for each goal?

Signatures and dates (lead clinician, family, coordinator, other):