



Community Support Plan (CSP)

ABOUT ME

SHAHAR R NOOR

Assessment Date: 11/03/2020

Plan Dates: 01/01/2021 to 12/31/2021

Developed by: Amy Heimkes (651) 430-8327

Address: 137 MYRTLEWOOD CT

STILLWATER, MN 55082-4688 County: Washington

Home: (651) 353-9920 Work: Other:

General Plan Notes:

CASE MANAGER: Jill Schaeppi Phone: 651-497-8650 Email: Jill.Schaeppi@co.washington.mn.us

PROGRAM(S): *Developmental Disabilities Waiver with CDCS & Rule 185 Case Management*

DATE THIS DOCUMENT WAS MAILED: 11/5/2020

STRENGTHS, ROUTINES, & DREAMS:

Shahar is a 30 year old female living in Stillwater with her parents (who are her legal guardians) and twin sister. There are no current plans to change her living situation, however future options are being considered. Typically, Shahar's routine includes attending Phoenix Alternatives, Inc (PAI) in Oakdale Monday through Wednesday. On the other days during the week, she spends time with her family participating in activities within her home and in the community. Due to the health emergency, Shahar is staying at home during the day, no longer attending PAI in person. She was participating in some remote services with PAI, however this is on hold due to PAI's staffing needs. Shahar will not return to PAI until it is safe for her to do so as she is at high risk. Shahar's strengths include that she loves to move (walk and dance), she communicates with her body, she loves to joke, and she loves to help cook. Shahar is a social light and she loves to travel. Her mom hopes to continue to travel at least once per year and that the family hopes to go on an RV trip around the country in the future.

SUPPORTS DISCUSSED:

Shahar receives consumer directed community supports (CDCS) through her Developmental Disabilities (DD) Waiver. Her Rule 185 case manager continues to monitor and coordinate her services to ensure they are best meeting her needs.

PERSON INFORMATION

Date of Birth: 02/25/1990 Age: 30 yrs

Emergency Contacts

Name	Relationship	Phone
Teresa Noor	Parent	(651) 353-9920
Ludfi Noor	Parent	(651) 353-9921

Notes/Comments

Decision Making Representatives

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Name	Type of Authority	Address	Phone
Teresa Noor	Private Guardian	137 Myrtlewood Ct, Stillwater, MN 55082	(651) 353-9920
Lufti Noor	Private Guardian	137 Myrtlewood Ct, Stillwater, MN 55082	(651) 353-9921

Notes/Comments

Health Insurance & Payers

Is the person certified disabled by Social Security or through the State Medical Review Team (SMRT) process? Yes

Is the person on medical assistance? Yes

Type	Describe	Policy Number	Effective Date
Medical Assistance	DX DISABLED/NO SUB-TYPE	01511523	06/01/2011
Medicare - Part A		6QV6H39GD67	07/01/2019
Medicare - Part B		6QV6H39GD67	07/01/2019
Medicare - Part D		6QV6H39GD67	07/01/2019

Notes/Comments

Providers

Health Care Providers	Phone	Comments
Primary Physician	(651) 326-5700	Robyn S. Tabibi, MD/ HealthEast Roselawn Clinic - Saint Paul, MN
Dentist	(651) 290-8707	Gillette Children's Specialty Healthcare - Saint Paul, MN
Pharmacy	(651) 439-7476	Walmart - Oak Park Heights, MN

Health Care Providers	Phone	Comments
Other	(651) 290-8707	Gillette Children's Specialty Healthcare - Saint Paul, MN
Hospital of Choice		
Other	(651) 432-4803	PICS - Saint Paul, MN
Fiscal		
Other	(651) 748-0373	PAI - Oakdale, MN 55128
Day program		
Notes/Comments		

WHAT'S IMPORTANT TO THE INDIVIDUAL

Goals related to how you want to live your life:

Quality of Life: To continue to walk around.

Activities of Daily Living: To receive caregiver support when completing all personal care tasks.

Instrumental Activities of Daily Living: To receive support completing all home and community tasks.

Health: To remain in good health, seeing her medical providers as needed.

Psychosocial: To receive helpful intervention from her caregivers when upset.

Memory & Cognition: To continue to receive DD Waiver services.

Safety & Self-Preservation: To feel safe in her home and in her community.

Sensory & Communication: To gain communication skills.

Employment, Volunteering & Training: To return to PAI when it is safe for her to do so.

Housing & Environment: To continue living with her family.

Self-Direction: To receive support with making decisions.

Caregiver: To receive primary care from her parents who best understand her.

Short and Long-Term Goals

Goal Statement	Target Date	Provider & NPI (if applicable)	Frequency of Reporting
To continue to walk safely.	12/31/2021		
To gain communication skills, possibly with eye gazing technology.	12/31/2021		
To continue to travel with her family.	12/31/2021		

Action Steps for Goals:

What will the person do?

Shahar will continue to participate in informal and formal support to build and maintain all skills necessary to achieve goals as recommended by the team and/or health care providers.

What will the case manager do?

Shahar's case manager will monitor ongoing supports and services and provide referrals or authorizations as needed to support her preferences, needs, desires and identified outcomes. Case manager will provide check-ins with Shahar and her team via phone or email as needed and will meet with her on a semi-annual basis or more as requested.

What will others do?

Shahar's parents/guardians will provide ongoing support, encouragement, advocacy, coordination of services, and access to additional supports and resources, as available and appropriate, to support her preferences, needs, desires, and identified outcomes.

are also waiting on a new ceiling lift. **DRESSING:** Shahar is dressed by her parents. She will sit on the side of her bed, and her parents will dress her lower and upper half. She will then stand up to have her pants pulled up. Shahar needs assistance putting on her corrective shoe and ankle-foot orthosis supports (AFO's). She also wears a helmet and a gait belt. **HYGIENE/GROOMING:** Shahar's parents complete her hygiene/grooming needs. She may yell as she doesn't like her face washed. Her parents have to be careful about her toenails as she is nervous during this task. Teeth brushing can be a challenge as Shahar has a hyper sensitive mouth, and she doesn't like when things touch her face. Her head does need to be held still. Shahar will try to swallow toothpaste so her parents use good quality toothpaste. To prevent her mouth from closing during the task, she has a tooth guard. **TOILET USE:** Shahar has no control of her bladder or bowels. She will have accidents in her brief during the day and night. She does have scheduled toileting times, however it is unpredictable if she will go or not during these times. She needs assistance with changing and cleaning. **MOBILITY:** Shahar is able to walk, but it is unsteady and can be unsafe. For example, she has fallen in the past resulting in a concussion and brain bleed. Shahar now wears a helmet. She requires one on one support when walking to ensure her safety when inside and outside of her home. It is important that her parents keep the ground clear as Shahar is vision impaired and she could trip and fall. She has difficulty walking fast, on icy or uneven terrain, and in unfamiliar areas. She has no depth perception which is a challenge for her daily. Shahar utilizes a wheelchair to the bus for PAI. She also utilizes a wheelchair as needed in the community. **POSITIONING:** Shahar has a curvature of her lower spine and needs to be repositioned frequently to help keep her spine as straight as possible to strengthen her spine. During the night, she is able to position herself as needed, however she may throw herself off the bed and she will need to be moved back into place. She has body pillows on her bed and her mom mentioned that she prefers to lay on her side while hugging a pillow. Shahar's bed also has side rails to increase her safety. **TRANSFERS:** Shahar's parents utilize a ceiling lift in the bathroom for bathing. Parents also use a lift for Shahar to utilize her chi machine. Her mom mentioned they use lifts for floor then up transfers. She can sit on her bed and then her parents swing her legs up onto her bed. Shahar is transferred to the van/bus in her wheelchair.

Home Management: Shahar benefits with support completing all home and community tasks. **MEDICATION MANAGEMENT:** Shahar's parents reorder, set-up, and administer her medications. Her pills are added into her food and her CBD oil is provided via syringe. **MEAL PREPARATION:** Shahar likes to be in the kitchen when her dad cooks as she loves to eat food. She likes to assist with hand over hand assistance. She can become aggressive when others are cooking. She doesn't understand kitchen safety, she may push on her parents back as they cook or she may try to touch the stove when it is hot. Shahar may push into others as they are eating and knock things off the counter. **TRANSPORTATION:** Shahar requires a wheelchair accessible van to safely access the community. In 2018, Shahar's family van was modified to add an electronic captain's chair to safely transfer Shahar in and out of the vehicle. This allows her to stay well supported and safely fastened in the captain's chair during transport, rather than riding in her wheelchair which can be uncomfortable for her. PAI drives her to and from the program. **HOUSEWORK:** Shahar's parents complete all of the housework. **TELEPHONE USE:** Shahar's parents complete all calls to address her needs. **SHOPPING:** Shahar enjoys shopping at the mall and grocery store. Her mom mentioned that Shahar finds the grocery store hilarious. Shahar will utilize a wheelchair when shopping as needed. **FINANCES:** Shahar's parents oversee her finances and are her rep payees.

Health Related/Medical: Shahar's health is reported as good. Her mom mentioned concerns in regards to her recent seizure

What will the provider do?

Chosen service providers will provide services to help support Shahar based on her preferences, needs, desires and identified outcomes.

SUMMARY OF NEEDS

Quality of Life: A good day for Shahar is when she can walk around. She enjoys sunny days and walking outside. Shahar loves cooking and eating the food even more. She also loves fireplaces. A bad day for Shahar is when she is confined and not able to walk around. She doesn't like being left alone, cold, or in pain. Shahar enjoys being with other people, but she may become overstimulated after a prolonged period of time with lots of action and commotion. She likes dancing, being massaged, walks, spending time outside, watching movies- especially comedies and action films, art and crafts, sensory activities, eating, cooking, story time, being in water, and being near children. She likes listening to music, including music by Beyoncé, Mariah Carey, and Taylor Swift. She also likes to watch HGTV and the show Bones. Shahar loves doing home visits with elderly folks. She likes to travel, and she likes to go to Duluth and Lake Superior. Lately, Shahar and her family have been going on drives and taking road trips, which she seems to enjoy. Shahar enjoys spending time with her family. She also enjoys her many friends at PAI and she looks forward to being with them.

Personal Assistance: Shahar benefits with caregiver support when completing all personal care tasks. **EATING:** Shahar anticipates and enjoys eating. She has a history of choking and has a difficult time chewing and swallowing safely. She needs hand over hand in feeding as she cannot use her hands purposefully, and she needs her caregiver to remind her to chew her food completely and to swallow. Shahar's mom mentioned that she doesn't exactly chew, as she will often just swallow her food. She is working on chewing and swallowing snack foods, like Cheetos. Her food is often ground up with a food processor. Shahar has gastrointestinal issues and requires a special diet to help her feel better and have fewer issues that cause discomfort. She is lactose sensitive and follows a low glycemic diet. She avoids dairy due to sensitivities, but will receive digestive enzymes and eat yogurt and once in a while ice cream. She avoids all processed foods, soda, nuts, and anything with additives and chemicals including aspartame. A light tap on her throat is helpful to cue Shahar when to drink. She has a gag reflex that will sometimes cause her to throw-up, especially if the food gets easily stuck in her throat, like bread. Shahar wears a bib and she always utilizes plastic dishware and utensils as she will bite down on these items. **BATHING:** Shahar doesn't stand in the shower due to the risk of slipping and falling, so she sits in the shower chair. Shahar will have a seizure when the temperature changes too quickly on her body, so the bathroom and the water needs to be warm to prevent a seizure. Caregivers put a towel on her at first to keep her warm, and then they take the towel off once her body becomes used to the temperature change. If Shahar takes a bath, she will be lifted via ceiling lift into the tub. She requires two people to bathe her and keep her safe. Her mom mentioned they are waiting to receive a new sling that will allow Shahar to sit upright in the tub, which will hopefully only require one person to bathe her. They

activity. Shahar went to the emergency room twice in the past year, one time due to pneumonia. She is at high risk for pneumonia due to aspirating. The other time was a result of a seizure that caused Shahar to fall and hit her jaw, 911 was called and then she was transported to the emergency room by her parents. Shahar was cleared, but it was determined that she has an increased risk of seizure due to a sensitivity to light and reflective surfaces. Due to this fall, Shahar will need to have her teeth checked to ensure there was no damage there. Shahar has a seizure disorder, other generalized epilepsy and epileptic syndromes, not intractable, without status epilepticus (G40.409), which her mom described as uncontrolled at this time. Shahar does experience atonic or drop seizures of up to 90 seconds to 3 minutes in duration. Her mom said that after a seizure, she will sleep for about 45 minutes. Her seizure medication, Lamotrigine, causes sensitivity to the sun. She can only be exposed to sunlight for 15 minutes as she is prone to skin cancer. Shahar experiences frequent headaches, and she will rub her eyes when she has one. In 2016, Shahar experienced a fall at PAI that resulted in a skull fracture and months of recovery. She was receiving MRI's after the fall due to brain bleeding, and it eventually drained on its own. Shahar experiences a reverse reaction when taking Vicodin and related medications, as it makes her hyper. She is to avoid these types of medications. Shahar is on top of her preventative health care needs as her parents ensure her medical appointments are scheduled and attended. She saw her primary care doctor one time, remotely, in the past year for a check-in. Shahar also saw her neurologist a couple of times in the past year, one time was remotely. Shahar is diagnosed with age-related osteoporosis without current pathological fracture (M81.0), resulting in very brittle bones and easy breakage. She has had 14 broken bones in her legs. Shahar has a 49 degree curvature of the spine that creates pain and balance issues. One leg is shorter than the other and she wears a corrective shoe. Due to her condition, Shahar has a hard time breathing, she will hold in and swallow air all day long. She will throw her head back after holding her breath and wait until she is blue until letting it go. Shahar's mom said her breathing gets worse during her monthly cycle. Shahar experiences undesirable side effects in result to her monthly cycle, including the breathing concerns, but also increased aggression and difficulties sleeping. Shahar sleeps well through the night when she is not experiencing her monthly cycle. When she has her monthly cycle, she will yell, scream, and moan during the night. She may fall out of her bed and her parents will catch this on the camera in her bedroom. Shahar clenches her teeth, and this can worsen during her cycle causing her to bite others or items. Shahar's parents will provide her with CBD oil during this time, especially to help her with sleep. Shahar experiences incontinence and her mom reported concerns about UTI's due to being in briefs at all times. Diarrhea and constipation is a concern for her, however as long as her diet is managed this is less of a concern. Shahar is at risk for ear infections and has issues with earwax. Shahar is at risk for heart issues, her heart is checked every five years and there are currently no concerns. She experiences mild psoriasis on her scalp. Shahar receives and loves her weekly in-home massages. Her mom reported she hopes to increase this to twice weekly as it helps with Shahar's rigid body. Shahar also uses the Chi Machine and a warm bath to cope with her pain. In the past, Shahar participated in swimming at Courage Kenny, but they discontinued this due to needing a support staff to bring her as Shahar's mom is allergic to chlorine and her dad can't assist due to his heart concerns. Shahar's mom hopes to find a staff/volunteer that can bring her to swim.

Cognitive and Behavior Supports: Shahar is sensitive to sound or too much stimulation and as a result can scream and cry for long periods of time. She will also become upset when she doesn't get her way or if she is in pain. Shahar experiences increased aggression during her monthly cycle. It is important to stay calm while Shahar is upset because if others are angry, she

will become angrier. She clenches her teeth, and this can worsen during her cycle causing her to bite others or items. Shahar's parents will provide her with CBD oil during this time, especially to help her with sleep. Shahar may bite her fingers, or hit her hands when she is anxious. She will bruise herself due to banging onto things when testing where items are in her environment. Shahar also needs to be watched so she doesn't knock over and break items. Shahar may push others with her body. She may drool on others and get into the faces of others, especially if they have food. Shahar may put her hand in someone's food and she will eat whatever she gets in her hands. She loves to kiss and may try to kiss others. In inappropriate places, Shahar may scratch herself near her brows due to irritation. If Shahar is not hand and hand with a caregiver, she will take off when outside. She thinks it is a game, and when she was younger, she had ended up in the middle of the road and another time hiding in a shed. It is important for all caregivers to stay hand and hand with Shahar. Shahar is susceptible to victimization putting her at risk of harm or exploitation. She requires a 24 hour level of care and supervision.; Shahar is diagnosed with Rett's syndrome (F84.2) and severe intellectual disabilities (F72). Based on the information available, Shahar qualifies for I/DD case management according to Rule 185. Shahar's needs have not changed in this area based on previous assessment. Rule 185 case management should continue at this time and a MnCHOICES assessment should be offered to Shahar on an annual basis to redetermine eligibility for services.

Personal Security: Shahar is considered a vulnerable individual and is at risk of neglect, abuse, or exploitation by another person. Shahar requires a 24 hour plan of care, supervision, and support (verbal and physical prompts) to be successful with self-preservation. Shahar receives staff and family support to ensure her health and safety needs are being met. Shahar will receive support from her staff and family in the case of an emergency.

Communications: VISION: Shahar has impaired vision. Her mom mentioned that she tends to "see" with her feet and body. She will use them to figure out where things are. Shahar's caregivers ensure the ground is clear to avoid her tripping and ensure her safety. She used to wear glasses, but she refused to keep them on. Due to her sensitivity to light which causes seizures, Shahar must wear sunglasses with UV protection outside at all times along with a hat. She will even wear sunglasses inside if the curtains are up. Shahar's mom is considering having her vision checked again to see where things are at. HEARING: Shahar's hearing appears to be borderline normal range, but it is difficult to assess. COMMUNICATION: Shahar is able to express her feelings of happiness by smiling and discomfort by breathing heavily or crying out. Her mom said she communicates with movement and with her eyes, mentioning that she sometimes answers yes or no questions with her eyes. She has used switches to activate equipment or augmentative devices with her head, nose, lips, chin, or cheek. She is not consistent in using one body part over another. Since the activation switch needs to be in the range of her head, it is sometimes inadvertently activated by her started movements (she begins to roll her head to get her body moving). Shahar does not seem to like using the adapted switches. She is not currently using any communication devices. She has limited receptive language skills and no verbal language. The Eye Gaze computer and software are being considered by her parents. Her mom did mention it could be challenging for Shahar to use the Eye Gaze computer as she is always in motion. She said it may be helpful if Shahar got a stand that can move or just stays upright as she doesn't want to sit. SENSORY: Shahar as some issues related to sensory input. She has sensitive hands. She likes music, but if she has music on and too many people around, she will become overly stimulated which can result in screaming. Shahar's mom mentioned that it helps for Shahar to go to her bedroom or a quiet space when overly stimulated. Shahar is sensitive to

temperature changes and she doesn't like the cold weather. She loves to be in the warm.

Employment/Training/Skill Building: Due to the health emergency, Shahar is staying at home during the day, no longer attending Phoenix Alternatives, Inc (PAL) in person. She was participating in some remote services with PAL, however this is on hold due to PAL's staffing needs. Shahar will not return to PAL until it is safe for her to do so as she is at high risk. Typically, Shahar attends PAL in Oakdale every Monday through Wednesday. She does not work, and rather participates in leisure and activities. Shahar enjoys going on outings with PAL and socializing with her peers. She participates in a variety of enrichment groups and activities. Shahar wears a helmet and gait belt at all times when she is at PAL. In 2016, Shahar experienced a fall at PAL that resulted in a skull fracture and months of recovery, so the helmet and belt are utilized to reduce her risk of falling and injury.

Supportive Services: Shahar lives in Stillwater with her mom, dad, and twin sister. Shahar's home environment is familiar to her, her mom mentioned she likes to walk her "circuits" within her home. Due to Shahar's risk of seizure when exposed to light, soon the homes outside aluminum railings will be painted and UVA blocking blinds will be installed to stop reflective lights from affecting Shahar. Shahar's mom reported that they have started a conversation in regards to moving in the next 5 to 10 years. She said they are considering looking into a group home setting for Shahar and her sister in case if something happens to her and Shahar's dad. Shahar's mom said they may sell their home and then buy two homes next to each other, one for the girls (and other potential housemates) and another for the parents.

Self-Direction: Currently, Shahar's parents are her legal guardians and they are also a great asset for Shahar and a great resource for assisting Shahar with making decisions.

Caregiver/Parent Support: Shahar's parents are paid parents for her under the consumer-directed community supports (CDCS) program. Her sister-in-law is a respite caregiver for her. Shahar's sister-in-law and her older brother, who live in Shoreview, will help out by staying over at her house when her parents need time off. They typically help out a few times per year for a few days or more at a time. Shahar has visits from a couple of volunteers who come over about once per month for a few hours. They tend to read to her and help with a meal. Shahar's mom reported they have a support staff who assists with a bath every week, however they hope to also receive support with a meal every week too. Shahar has a younger sister who moved to Denver, who will provide respite support as able when she visits home.

RECOMMENDED REFERRALS

Sensory & Communication: Referrals Needed: Assistive Technology - Eye Gaze computer and software

Housing & Environment: Referrals Needed: Other - group home setting options for the future

INFORMAL CAREGIVERS

Name	Caregiver Relationship	Lives with Person	Caregiver Role	Type of Care
Teresa Noor	Parent	<input checked="" type="checkbox"/>	Primary Caregiver	<input checked="" type="checkbox"/> ADLs <input checked="" type="checkbox"/> IADLs <input type="checkbox"/> Habitatation <input checked="" type="checkbox"/> Community Access <input checked="" type="checkbox"/> Supervision <input checked="" type="checkbox"/> Social Interaction <input checked="" type="checkbox"/> Health & Medical
Luqfi Noor	Parent	<input checked="" type="checkbox"/>	Primary Caregiver	<input checked="" type="checkbox"/> ADLs <input checked="" type="checkbox"/> IADLs <input type="checkbox"/> Habitatation <input checked="" type="checkbox"/> Community Access <input checked="" type="checkbox"/> Supervision <input checked="" type="checkbox"/> Social Interaction <input checked="" type="checkbox"/> Health & Medical

Notes/Comments

RISKS

How will Health and Safety Issues be Addressed?

Shahar's health and safety concerns/issues will be addressed in her CSSP as well as her IAPP, SMA, and CSSP addendum from her formal providers. She will be provided a 24 hour plan of care and supervision to ensure her health and safety.

NEXT STEPS:

- You will work with an assessor or case manager to develop a Coordinated Services and Supports Plan for the public program you have chosen.
- We are waiting for:
- For help locating services and supports options in this Community Support Plan, these are resources you can contact:
 - www.Minnesotahelp.info®
 - Disability Linkage Line® (Hub) 866-333-2466
 - Senior LinkAge Line® (SLL) 800-333-2433
 - Veterans Linkage Line™ (VLL) 888-546-5838

Comments:

