



Handbook for Participants, Families and Guardians

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Note: For simplicity in reading and understanding this document, whenever "family" or "parents" is used in this handbook, please interpret it to mean those relatives who provide primary support to the participant or the guardian of the participant in the same or similar role.

1) Welcome

Welcome to **Forward Journey Adult Day Services**. The purpose of this handbook is to acquaint participants, parents and caregivers with Forward Journey in order to make the transition into our program as smooth as possible. There are several things to keep in mind about this handbook. First, it contains general information and guidelines. It is not intended to be comprehensive or to address all the possible applications of, or exceptions to, the general policies and procedures described. For that reason, **if you have any questions concerning a particular issue and how it applies to you or your participant, please address your specific questions to the Program Manager/Program Specialist or the Executive Director.** Neither this handbook nor any other company document confers any contractual right, either express or implied, to be a participant of Forward Journey.

a) History and Mission of Forward Journey Adult Day Services

Incorporated as Collaborative Effort to Reinforce Transition Success, Inc. and using the acronym C.E.R.T.S., our doors opened in October 2006 to support young adults with multiple, severe disabilities as they transitioned from school to adult life. As these young people have aged, our support has expanded to include all adults with multiple, severe disabilities who have the potential to be active. The program was developed for the 1% of the general population (or the 10% of those individuals with disabilities) who are MOST significantly impacted by their disability. Forward Journey currently operates two sites in the state of Delaware; our main headquarters in New Castle County and a second site in Kent County. To be able to serve individuals and families who need the level of care for which Forward Journey is known, our vision includes having locations throughout Delaware in all three counties.

Forward Journey Adult Day Services is an activity based, individualized program where participants make choices as to which activities they would like to be a part of each day. In addition, a nurse is on duty at each site all day, every day which is very unique for a program like ours. Access to therapies is an additional benefit of attending Forward Journey. We currently have a contracted physical therapist consulting at both sites.

Building physical strength is a critical part of the programming offered at Forward Journey Adult Day Services. Guided by the MOVE® (**M**obility **O**pportunities **V**ia **E**xperience/Education) program, participants have adapted walkers called Pacers® and/or other specialized equipment. MOVE® helps our attendees acquire increased independence in sitting, standing and walking in order for them to experience better health and enhanced personal dignity. MOVE® produces results through hard work, repetition and the dedication of our trained staff. (For more information on MOVE®, please see Appendix A).

Each individual's program is outlined in the Life Span Plan (LSP) and focuses on the development and reinforcement of basic self-help, communication, functional mobility, community outings, recreation, and daily living skills. **The mission of Forward Journey is to enrich the lives of adults with multiple, severe disabilities and, in turn, their families through an active personalized day program.**

b) Quick Facts about Forward Journey Adult Day Services

- i) Non-profit – The company has a 501(c)3 status as tax exempt under IRS regulations. As such, donations are tax deductible to the fullest extent of the law.
- ii) Average age of participants (as of September 2022) is 32 years.
- iii) Targets a Specific Population: Forward Journey was developed with the express purpose of supporting individuals with severe, multiple disabilities. This population is often not able to be served in other day programs due to their support needs. (For more information on Admission/Discharge Criteria, please refer to Appendix B).
- iv) MOVE® for Adults Model Site – In 2009, the company became the first MOVE® for Adults Model site in Delaware (only the third world-wide). We are very proud of this distinction because it allows us to provide best practice support to our participants as well as gives us the opportunity to demonstrate the MOVE® for Adults philosophy in action to individuals and agencies who are interested in becoming MOVE® certified.

- v) Oversight – Forward Journey is led by a volunteer board of directors who are responsible for setting the mission and vision of the agency, which the staff carry out. The board of directors is also responsible for the fiscal health of the organization. To ensure success, there are several standing board committees, including finance, personnel, fund development, board development and program quality. If serving on the board is of interest to you, please contact the Executive Director for more information.
- vi) Funding – the majority of funding for Forward Journey comes from a contract with the State of Delaware, Department of Health and Social Services (DHSS), Division of Developmental Disabilities Services (DDDS). As a “provider agency”, Forward Journey must adhere to strict guidelines as outlined in the contract in order to be reimbursed for the support of eligible clients of DDDS. The amount of funding varies for each person served, depending upon the level of support required, as identified through a DDDS assessment known as Inventory for Client and Agency Planning (ICAP).
- vii) Budget – The contract funding noted above through DDDS covers approximately 90% of our annual budgeted expenses. The additional 10% needed is acquired through special events, individual donors and grant awards. Fundraising necessary dollars to fill this funding gap is critical in maintaining our fiscal solvency. It means so much when our parents/participants assist us to meet our mission by contributing toward the difference between our contract funding and our budgeted costs. Not only is the donation tax-deductible, but it benefits your participant when we can bring in additional activities such as art and pottery, and purchase assistive technology equipment.

c) Non-discrimination policy

Forward Journey provides equal opportunities for all participants and applicants for admission without regard to race, color, religion, gender, sexual orientation, gender identity, national origin, age or marital status in accordance with applicable federal, state and local laws. Admission is granted if there is a program match between the needs of the prospective participant and the ability of Forward Journey to meet those needs. For more information regarding admission or discharge of a participant from the program, please refer to Appendix B, Admission & Discharge Criteria.

2) What should I expect from Forward Journey Adult Day Services?

- a) Well trained staff providing exceptional support – All employees of Forward Journey are required to undergo training within their first 90 days of employ. Those providing direct care to participants have extensive training (and annual recertification) on a number of topics, including seizure management, safe feeding, MOVE® Basic Provider certification, CPR/First Aid, universal precautions, lift training, fall precautions, medication administration, wheelchair safety on community outings and much more.

The policy of Forward Journey is to augment the training which is required under our DDDS contract with additional teaching on areas specific to serving adults with significant support needs. We see a direct correlation between the additional training and the ability of the staff to safely support participants.

We are also very particular and diligent with our hiring process. For example, applicants who will be providing direct support are required to undergo a three-step process which includes an interview with at least two senior staff, a few hours spent “job shadowing” during the program day, and successfully passing several checks, including criminal background, fingerprinting, drug testing, physical/lift test, and adult and child abuse registry; all to ensure the safety of the participants.

The job shadowing is the most unique aspect of the process. It requires the candidate to interact directly with the participants and existing staff. The staff paired with the candidate ensures they are comfortable with the duties being explained and has a good initial rapport with the participants. Note: candidates are not left alone with participants, do not lift participants or provide other direct support which could be dangerous if not well trained. This process has been valuable in selecting employees who display the appropriate skill set and professionalism or revealing those who are uncomfortable with the job duties or the individuals served.

- b) Good communication – you should expect to receive regular communication from various individuals at Forward Journey with regard to a number of details pertinent to your participant:
- i) A note is sent home daily in the communication book detailing the day’s activities, amount of food eaten, number of times voided, and anything special or unusual observed that day.
 - ii) A note will be sent in the event additional supplies are needed, such as attends, wipes or prescription drugs.
 - iii) If your participant has a seizure that doesn’t require additional medical intervention, a copy of the seizure report will be sent. Note: for information about emergency response such as the need to have a participant sent to the hospital for a seizure or other condition, please see Section 10, emergency procedures.
 - iv) Depending upon the severity, a note will be sent home or the nurse will call the participant’s main contact to report a bruise or other injury; whether sustained at Forward Journey or observed upon arrival. If the participant is injured at Forward Journey and the injury is captured on video, parents/family/guardians may request and will be allowed to view the video. Due to privacy issues, Forward Journey is unable to release a copy of the video.
 - v) Email or telephone contact will be made to schedule an annual Life Span Planning (LSP) conference or any other needed meeting to discuss the progress of your participant.
 - vi) If there is a new behavior manifesting or a change in typical habits, contact will be made in an effort to understand what is going on, see if these changes are also observed at home and offer support to all involved.
 - vii) If your participant becomes ill during program hours and needs to leave, a senior staff member will call the main contact with this information. If the main contact is unavailable, emergency contacts will be notified and asked to assist. For more on emergency response, see Section 10.
- c) Regular Life Span Planning (LSP) conferences – Just prior to admission, there is a transition planning conference where the initial LSP is created and discussed with all interested parties, including the participant, the parent(s)/guardian(s), the DDDS case worker or community navigator, the Forward Journey Nurse and Program Manager/Program Specialist. LSP conferences will be scheduled annually thereafter, unless a change in status indicates the need for an interim meeting to update the plan of care outlined in the document. The purpose of these meetings is to discuss progress of the individual with the plans outlined in the prior document and set new goals for the coming year. Note: For those participants who do not live with natural families, DDDS is responsible for scheduling and running the annual LSP conferences, which are usually held at the Forward Journey sites. Staff members of Forward Journey attend these conferences, but have significantly less control over the quality, content and outcome.
- d) Excellent customer service – Forward Journey was created by parents of individuals with severe, multiple disabilities, among others. Our goal is to create a fun, personalized day for each participant, giving them the ability to decide what they want to do each day and supporting them to access their chosen activity while supporting each with nursing and therapy consult as appropriate. In order to achieve this goal, it is imperative to provide excellent customer service to the people we serve.
- i) Who are our customers?
 - Participants
 - Family members/Guardians
 - Donors
 - Volunteers
 - Case workers/Community Navigators
 - DDDS
 - Vendors, service suppliers

- ii) How do we provide excellent customer service?
- By providing the supports and services to participants/families as outlined in the LSP
 - By communicating regularly with all of the above customers in order to bring needed supports and services to the participants
 - By performing all services in a polite, professional manner
 - By being available to meet with parents to discuss issues of concern
 - By readily admitting mistakes when made and endeavoring to be better in the future
 - By being open to constructive criticism which is given in order to improve supports and services to the participants

- 3) **What we expect from parents/guardians.** In order to be able to provide the highest quality support available for participants, it is imperative that families commit to the following:
- a) Provide current telephone numbers for primary and secondary contacts for general use and in case of emergency.
 - b) Ensure the correct address, telephone numbers and email addresses are on file, updating immediately upon changing any contact method.
 - c) Communicate with Forward Journey regarding concerns, changes in health, disturbed sleep or anything that could impact the day for the participant. This includes notifying the Program Manager/Program Specialist of your participant's absence from the program, or late arrival/early departure.
 - d) Abstain from sending your participant to Forward Journey if s/he is sick. The individual must be fever free for 48 hours before returning to program.
 - e) Provide prescription refills as soon as possible after requested.
 - f) Ensure adequate supplies for your participant – attends, wipes, and tube feeding supplies (if needed). We request that you routinely send an adequate supply.
 - g) Timely arrival and departure. When participants arrive late, two staff members must leave the six individuals they are supporting to assist the new arrival with toileting, etc., negatively affecting those who did arrive on time. When participants depart late, staff members may be due overtime pay.

4) What time is everything?

- a) Hours – The doors to the program open at 8:45 as a courtesy. Program hours are 9:00 a.m. until 3:00 p.m. Monday through Friday. Please make every effort to pick up your participant, or have the bus pick up your participant at 3:00 p.m. The agency is open until 3:30 p.m., allowing staff to complete required chores, enter required participant data into the DDDS client record system, set up for the following day or complete training. If the participant is not picked up by 3:30 p.m., a call is made to the transportation provider (whether this is the parent or DART, etc.) reminding them that a participant is waiting for a ride home.
- b) Annual Calendar – In December of each year we will send home the annual calendar for the upcoming year. The calendar includes information on holidays, board meeting dates and any scheduled staff in-service days.
- c) Holidays – Forward Journey is closed in observance of the following holidays, which are noted on the annual calendar:
 - New Year's Day (January 1)
 - Good Friday (the Friday before Easter)
 - Memorial Day (the last Monday in May)
 - Juneteenth (June 19th)
 - Independence Day (July 4)
 - Labor Day (the first Monday of September)
 - Thanksgiving Day (the last Thursday of November)
 - Black Friday (the day after Thanksgiving Day)
 - Holiday Break from Christmas Eve Day (December 24) through December 31.
 - One rolling holiday, voted on by staff members and approved by the board. This is often, but

not always, attached to another holiday to make a long weekend/extend the time off.

- d) Staff In-service days – up to four (4) days per calendar year are set aside for specialized training and staff development. When possible, these are noted on the annual calendar. When this is not possible, notice of the closing is sent to caregivers with at least 2-weeks’ notice in the following ways: note home in communications log, email notice, posting on the Forward Journey website (www.forwardjourney.org) and Facebook page. We also inform DART Paratransit and private transport companies in advance of the closing. It is important to be aware of pending in-service days; Forward Journey staff may not even be onsite to provide support if a participant arrives at Forward Journey when the program is not open.
 - e) Incident Weather Closing – Closures due to bad weather typically happen between December and February. Notice of closing is posted on WSTW 93.7 FM, WDEL 101.7 FM, and WDEL 1150 AM via the SnoWatch program. SnoWatch information is also available online at the radio station’s websites: wdel.com and wstw.com. **The decision to close is made independent of area school closings.** We try to stay open when possible, in order to accommodate those families who must work regardless of weather conditions; however, we balance this need with the health of our staff and the relative safety at each location. Because weather conditions vary between local areas, one Forward Journey site could be closed on a particular day, while the other is open.
- 5) **What should participants wear to Forward Journey each day?** We have the following recommendations:
- a) Comfortable, weather appropriate clothes. Some activities can be messy, and we like the participants to have fun, so don’t send fancy clothes. We try to cover the participants’ clothes during painting sessions, but fun happens!
 - b) Pants that are easy to remove and adjust during personal care. Elastic waistbands are great, but please no tight pants or button fly jeans.
 - c) Please send several extra sets of clean clothes for us to keep at Forward Journey in case of a bathroom accident. If your participant has a tendency to leak through, you must send in extra clothing or we may have no choice but to send him/her home in wet/soiled clothing. We do NOT want to do this. Unfortunately, we are unable to launder soiled clothing for participants. When clothing is changed at Forward Journey it is sent home for laundering in a plastic bag.
 - d) If no clean clothes are on hand for a participant, we have a few company-owned pants and shirts which we put on participants for the remainder of the day. Through the years, we have consistently had problems with these “spare” clothes not being returned by the borrowing participants or family. We have run out of these in the past and participants have not had fresh clothes to wear. Please help us avoid this by:
 - i) Sending in extra clothes for your participant (2-3 changes of pants and tops)
 - ii) Promptly laundering and returning borrowed items
 - iii) Donating unneeded clothing (pants with elastic waistbands, t-shirts and sweatshirts work well)
- 6) **What to eat?**
- a) Upon admission a form is completed which indicates what type of diet a participant requires. Examples of food requirements vary from eating cut up food independently to puree diet to tube feeding.
 - b) **Food MUST be sent in as it is to be eaten. Pureed food must already be pureed, bite sized sandwiches should be cut into bite sized pieces. Cold food can be heated, but for safety all prepared food must be ready to eat.**
 - c) If liquids need to be thickened, a doctor’s note must be provided, detailing the consistency needed (nectar, honey, etc.). Examples of liquid restrictions range from no restrictions to thickened drinks to nothing by mouth.
 - d) Whenever a change in diet is required, an updated doctor’s note must be received.
- 7) **What to bring each day?**
- a) As noted above, extra pairs of clothes (especially pants) in case of accident
 - b) Enough attends or other personal care garment for the day (extra can be sent in, but storage space is limited, no cases)
 - c) Wipes – for your participant only; we will notify you when more are needed

- d) Chuks or Blue pads, if needed for your participant
- e) Any AFOs or other adapted equipment your participant needs
- f) Medical equipment or needs (i.e., VNS for seizures)
- g) Participant Communication Book

8) What about doctor's appointments?

- a) Most of our participants are late from time to time due to a doctor visit or other appointment. Please let us know of the appointment and approximately what time to expect your participant. If the individual arrives after the lunch period is over, please ensure that s/he has been fed or remain to feed him or her. Staff is unable to assist with feeding after the lunch period has ended.
- b) When a participant needs to leave early, please contact the Program Manager/Program Specialist that morning and indicate the time s/he will be picked up. If we know of the need to leave early, we will have the participant ready with no waiting required.

9) What about illness?

- a) Many of our participants are immunocompromised, meaning that if they are exposed to viruses or other germs or communicable diseases, they are more likely to get sick than the general population. Our participants are also not able to cover their mouths when they cough, or their noses when they sneeze, thus making transmission easier than usual. For these reasons, we request you do not send your participant to the program if they exhibit signs of illness. Just as you don't wish to get sick from another individual, other families don't wish illness on their loved ones. The only way to protect the group as a whole is to abide by this rule of common courtesy.
- b) If a participant arrives at Forward Journey with a fever, excessive coughing and mucous, diarrhea, vomiting or other communicable illness (conjunctivitis or pink eye, for example), we will call and request the participant be picked up from the program immediately. This is to protect other participants from contracting the illness, as well as our staff. If staff become sick and unable to work, the entire program suffers. If there is a reasonable concern for the safety of the participant or those around him/her, the nursing staff may require a doctor's note before the participant is able to return to Forward Journey.
- c) Due to the limited nursing resources available at Forward Journey, we are unable to provide the following interventions/treatments:
 - i) Oxygen
 - ii) Catheterization
 - iii) Nebulizer treatments (scheduled or PRN)
 - iv) Vest treatments
 - v) Suction
 - (1) Nasal tracheal suctioning – unable to provide
 - (2) Oral suctioning – can be provided PRN. Due to time constraints on the nurse, if a participant requires more than two (2) interventions in a program day for several days, the Director of Nursing may require the participant to remain at home until the situation has resolved.

Should a participant need the above after recovery from illness, please contact your case worker/ community navigator to discuss obtaining additional nursing supports for him/her.

10) What happens in the event of a medical emergency, such as a seizure?

- a) Many participants have a documented seizure disorder. Each participant has a unique protocol, outlining what procedures are to take place in the event of a seizure. This protocol is developed for use at Forward Journey (including outings) in conjunction with the participant, the family and the physician.
- b) If protocol dictates an ambulance must be called (depending upon the specific needs of the participant) the contact person of record will be notified immediately and told where to meet the ambulance.
- c) If no response is received, we will call the other listed emergency contacts for assistance in the situation. For more on seizure protocol, feel free to speak with the nurse at either location.

- d) In the event of a suspected head injury, the participant will immediately be transported to the emergency room by ambulance and the contact person on record will be notified. Forward Journey nurses and program managers have the final authority to arrange for emergency treatment while the participant is in Forward Journey's care.

11) What happens in the event of other emergencies, such as the need to evacuate?

- a) Forward Journey Adult Day Services sites have separate emergency evacuation procedures appropriate to their location. Participants will travel via bus, van and/or staff vehicles.
- i) Local evacuation – evacuation order given to leave the building, but stay in the local area:
- New Castle County site – participants and staff will relocate to Easterseals, 61 Corporate Circle, New Castle, DE 19720; phone 302-324-4444.
 - Kent County site – participants and staff will relocate to Clayton Fire House, 300 East St., Clayton, DE 19938; phone 302-270-8652
- ii) Regional evacuation – evacuation order is given to travel more than 20 miles away:
- New Castle County site – participants and staff will travel to the Kent County site until the evacuation order is clear (699 S. Carter Road, Suite 1, Smyrna, 19977).
 - Kent County site – participants and staff will travel to the New Castle County site until the evacuation order is clear (52 Reads Way, New Castle, DE 19720).
- b) Other things to know for such an emergency:
- i) The urgency of the situation will dictate what equipment will be brought with the participants to the evacuation site. This means if the order is to drop everything and get out, the priority will be on evacuating PEOPLE, not equipment or supplies, although lifesaving necessities and first aid supplies will always be available during an evacuation. Wheelchairs may or may NOT be available, as the need to evacuate may require transport in non-accessible vehicles. We realize this is not the ideal situation, but our first priority is safe evacuation of the participants, then the staff, then equipment, in that order.
- ii) As soon as possible once the evacuation has occurred, caregivers will be notified of the emergency and told next steps, including the status of the emergency and the location of their participant. This could include a request to pick up participants at the evacuation site, it could be a notification of the evacuation with explanation that participants will be returning to the Forward Journey site at a specific time.

12) How can I get in contact with the people at Forward Journey?

- a) The main number for all locations is 302-731-0301. The prompts on the voice system will ask if you wish to speak to someone at New Castle (press 1) or Kent (press 2). If you know your party's extension, dial it at any time. There are additional prompts on the system for emergencies and for senior staff.
- b) The Board president can be contacted by leaving your name and contact information with the Executive Director or Operations & Human Resource Manager. The message will be forwarded to the Board member.

On behalf of the board, staff and our participants, WELCOME to the Forward Journey family! We look forward to working with you to further our mission to enrich the lives of adults with multiple, severe disabilities through an active, personalized day program.

Appendix A

The Theory behind MOVE® for Adults

- The MOVE® for Adults program is designed to provide adults with developmental or complex disabilities the opportunities and skills to participate more fully in a life of their choosing. It accomplishes this through the use of upright postures and the development of basic mobility skills needed to explore environments, participate in activities, and make informed choices based on personal preference and desires. (Whinnery & Whinnery, *MOVE® for Adults Program Manual*, 2009, p. 1)
- The core principles of MOVE® are aligned and recognized as current best practices for adult programming which call for increased engagement in age-appropriate activities. (*Ibid.*)
- MOVE® is an ecological approach that is used during naturally occurring situations throughout the day. It is not a “pull-out” program. Persons will naturally MOVE from activity to activity using their equipment as naturally as we use a car to get to and from our destinations. The seating, walking and transitions will be aided by equipment only as an assist, not as the goal. All the while, practitioners are learning and strengthening their skills by repeated opportunities to practice them throughout the day. MOVE® is hidden – working as an infrastructure to us at Forward Journey Adult Day Services. The methods and steps are used to further the independence of the individuals served.
- The goal is always for the individual to participate in all aspects of his/her day with as much independence as possible.
- Use of all other assistive devices, communication methods and computer skills are all vital parts of this theory and support the goal of maximum independence for each participant in every activity in the program and in the community. This is not in conflict with MOVE®, but is a part of MOVE®.
- Growth in social skills among our participants is a bi-product of communication and free Movement. Practice of these skills is evident as our participants choose who they want to associate with and which activities they choose.
- For more information, visit www.MOVE-international.org.

Appendix B – Admission & Discharge Criteria

Admission Criteria:

- Developmental/intellectual disability and other significant disabilities which impair the applicant's ability to perform three or more activities of daily living independently
- Minimum age is 21, unless prior approval is received from Delaware Division of Developmental Disabilities Services (DDDS)
- Ability to benefit from services provided by in a group setting with levels of staffing provided under current funding
- Able to participate and tolerate an active, fast paced environment which is often noisy
- Able to benefit intellectually and socially from the program offerings at Forward Journey
- Medical needs that can be safely supported by program nurse
- Clearance from physician for applicant to be able to be in a supported upright position* with the goal of active weight bearing*
- Clearance from physician to have a consultation** with the Physical Therapist upon admission to Forward Journey
- Willingness to accept agency policy against honoring "Do Not Resuscitate" (DNR) orders (if in place)
- Free from communicable diseases that pose a serious health threat as defined by public health authorities, including, but not limited to: tuberculosis, an active case of MRSA, active contagious skin conditions, infectious intestinal illness such as C-dif, etc.
- No issues with aggressive/violent behavior or other disruptive anti-social behaviors (e.g., hitting, biting, scratching, etc.)
- Eligible for funding via DDDS; we are unable to accept private insurance at this time

Discharge Criteria:

- Acceptance in an alternative day program or withdrawal from program by parent/guardian
- Excessive absenteeism
- Violent, disruptive or anti-social behavior which presents a significant danger to self or others or is disruptive to the program in general and has not been successfully controlled with appropriate support methods
- Presenting needs which cannot be met with available resources
- Inability to develop a plan of care for participant that is acceptable to the participant, parent/guardian and Forward Journey (e.g., complaints, displeasure with service/supports provided that are unresolved)

*Without medical contraindication. Examples of medical contraindication would be certain cardiac conditions, severe osteoporosis, etc.

**If this form is received, the admissions committee believes the candidate is sufficiently healthy and able to benefit from all of the program offerings here at Forward Journey (based upon past experience).