journeyforward

Letter of Intent for_____

BEGINNING

_____

(Date)

Authored by: _____

Adapted for siblings and their families based on Future is Now! created by the Rehabilitation Research and Training Center On Aging and Developmental Disabilities Department of Disability and Human Development-University of Illinois at Chicago.

Provided by

wisconsibs
Sisters & Brothers of People with Disabilities
WisconSibs, Inc 211 E. Franklin St, Appleton, WI 54911 – 920-968-1742 www.wisconsibs.org

We will JOURNEY FORWARD
and this is Our Letter of Intent

For: _____ Date: _____
Name of sibling with disability

This letter of intent was written by (may be one or more people):

_____ _____
Name Relationship to person with disability

_____ _____
Name Relationship to person with disability

_____ _____
Name Relationship to person with disability

_____ _____
Name Relationship to person with disability

_____ _____
Name Relationship to person with disability

Contact information for person with disability

_____
Name Email

_____
Address City State Zip

_____ _____ _____
Phones

Date of Birth: _____ Place of Birth: _____

Name and contact information of primary caregiver(s):

_____
Name Email

_____
Address City State Zip

_____
Home phone Cell phone Work

Our Story (where parents were born, where met, stories of individual's birth and childhood, individual's schooling, other sibling's stories, and any other material you wish to include):

Naming the Dream and Nightmare

My Family's Dream is (the best that could happen)**:**

My Family's Nightmare is (the worst that could happen)**:**

My (our) sibling's dream is:

My (our) sibling's nightmare is:

Goals and Next Steps (dream/nightmare)

Goals:

What our family, including my (our) sibling with a disability, wants for the future:

-
-
-
-
-

Next Steps:

Specify the actions you should take to achieve the goal(s).

1. **_____**
2. **_____**
3. **_____**
4. **_____**
5. **_____**

Building Relationships

Family members important to my (our) sibling:

Name	Address	Phone/Email	Relationship

Close friends that are important to my (our) sibling:

Name	Address	Phone/Email	Common Interest

Others important to my (our) sibling:

Name	Address	Phone/Email	Common Interest

Family Culture

Our family celebrates the following events (birthdays, holidays, anniversaries):

Our family celebrates events by:

Other cultural / ethnic information:

Building Relationships: Strengths and Preferences

My sibling: _____

Places my (our) sibling likes to be, or that make sense to try (e.g., places that create enthusiasm, motivation, energy):

What my (our) sibling enjoys:

My (our) sibling can do these things (competencies or abilities):

My (our) sibling would like to be/learn these things (new competencies):

These things are important to my (our) sibling (e.g., family identities and traditions, religious beliefs, relationships, indoor/outdoor activity preferences, day or night, structured or relaxed environment, quiet/noisy setting):

These are the best things about my (our) sibling (personal qualities, life-shaping experiences):

Disposition:

My (our) sibling's disposition is generally: (i.e. happy, playful, quiet, withdrawn, assertive, passive, easily influenced, etc.)

My (our) sibling might become upset / violent if:

This is how we calm / comfort him/her:

Communication

My (our) sibling uses speech to communicate Yes ____ No ____

Special information about my (our) sibling's communication:

Habits and routines

My (our) sibling is used to the following routines:

Morning

Day time

Evening

Bed time

Other

My (our) sibling has the following habits:

Goals and Next Steps (relationships)

Goals:

What our family, including my (our) sibling with a disability, wants for building relationships:

Next Steps:

Specify the actions you should take to achieve the goal(s).

1.

2.

3.

4.

5.

6.

Housing

Current living arrangement:

Desired future living arrangement:

List what is important in terms of location, transportation, grocery store, family members and friends homes, etc.

List types of places that would need to be conveniently reached from your sibling's home?

Level of independence

Level of mobility (e.g., ambulatory, wheelchair):

How residence needs to be adapted (ramp, grab bars, etc):

Household tasks that s/he can perform independently:

Household tasks that s/he will need help with:

Assistance needed with public transportation, shopping, hiring and firing own personal care assistants:

My sibling makes the following choices (clothing, spending allowance, pick out videos, etc):

Personal Possessions

Important items for my (our) sibling to have at his/her home: (i.e. collections, TV, computer, etc.)

Personal Care

My (our) sibling appreciates assistance with the following personal care tasks:

My (our) sibling is able to do the following personal care tasks alone:

My sibling is used to the following personal care items (i.e. brands of shampoo, soap, toothpaste, razor, etc.):

My (our) sibling is used to the following personal care routine:

Height: _____ Weight: _____ Clothing Size: _____ Shoe Size: _____

Describe how you best reinforce your sibling's self-esteem:

Food and Eating

My (our) sibling is able to do the following food preparation and clean up:

Assistance needed:

My (our) sibling likes the following foods:

My (our) sibling dislikes the following foods:

Special information regarding food and my (our) sibling:

Family customs regarding food:

Goals and Next Steps (housing)

Goals:

What our family including my (our) sibling with a disability wants for the future:

Next Steps:

Specify the actions you should take to achieve the goal(s).

1.

2.

3.

4.

5.

6.

Post-secondary education, work, leisure

Current education, work, or retirement activities (include organization name and contact person):

Activities my (our) sibling likes:

Unstructured activities (walks, shopping, etc)	Special Things to Know (special assistance needed, friends to go with, time of day)

Structured activities (concerts, church, trips, etc)	Special Things to Know (special assistance needed, friends to go with, time of day)

List Community Activities or organizations:

Leisure and Recreation activities:

Activities my (our) sibling does <u>not</u> like:

Vacations (past ones and future dreams):

Fitness Program or Health Club:

Types of activities he/she enjoys:

Does he/she vote: __No __Yes ___ Absentee ballot ___ In person

Other details:

Library member? _____ If YES, specify branch and location:

Clubs:

Religious or spiritual needs

Current religious institution affiliation (name, address and phone):

How has individual participated in religious community?

What aspects of religion/spirituality are important?

Funeral Arrangements (burial, cremation, cemetery plot, financial plan, type of service):

Goals and Next Steps (education, work, leisure)

Goals:

What our family including my (our) sibling with a disability wants for the future:

Next Steps:

Specify the actions you should take to achieve the goal(s).

1.

2.

3.

4.

5.

Who will be the keeper of the dream?

Our family, including my (our) sibling with a disability, has chosen the following person as the successor caregiver: (name of person with contact information)

My/Our Sibling's Medical Care:

Diagnosis: _____

_____

Current Doctors	Address	Phone	Experience with Doctor and Routine of Care

Medications:

Name of Medication	Dosage	What is it for?	Prescribed by?

Doctors **not** to go to (Explain why):

Medical services and therapies:

Dentist:

Allergies:

Ophthalmologist and Audiologist:

Important information regarding vision, hearing, devices, or special equipment:

Important information regarding seizures:

Past operations / conditions:

Sleeping habits:

Other important medical information (Genetic testing, immunizations, birth control):

Education history of sibling with disability

School Name	Dates	Comments

My (our) sibling has a current Individual Education Plan (IEP):Yes __ No__ Not Applicable __

If yes, important information about the IEP:

My (our) sibling currently has a transition plan: Yes __ No__ Not Applicable __

Important information regarding the transition plan:

What are the future educational needs of my sibling?

Why is this important to my sibling?

Financial/Legal Plans

I (we) have developed a special needs trust for my (our) sibling: Yes ____ No ____

Important information regarding my (our)sibling's special needs trust:

What to spend it on?	How often?	How much?

The Trustee of his/her trust is (Name, address, and phone):

The Advisor of the trust is (Name, address, and phone):

Guardian (Name, address, phone, location of documents) of the person:

Guardian (Name, address, phone, location of documents) of the estate:

Successor Guardian:

Power of Attorney:

Successor Power of Attorney:

My (our) sibling has a will? Yes ____ No ____Where is it located?

My (our) sibling has an advance directive for healthcare? Yes ____ No ____

Describe:

Financial Information

Representative Payee (Name, address and phone):

Receives SSI ____ Current Amount: _____ Medicaid Number: _____

Receives SSDI ____ Current Amount: _____ Medicare Number: _____

Other income or assistance:

Funding

My (Our) sibling is enrolled in ___ Family Care __ IRIS

Details for contacting consultant (name, phone, email):

Aging and Disability Resource Center (ADRC) case manager:

Banking

Bank/Credit Union Name: _____

Address: _____

Contact person and phone: _____

Savings Account Number: _____

Checking Account Number: _____

Paychecks

Amount of paychecks: Dates paychecks are issued:

Uses paychecks for:

Does own banking: Yes _____ No ____

Specific assistance needed:

Tax Information

Accountant Name, Phone, Email:

Can do own taxes: Yes ____ No ____

Specific assistance needed:

Goals and Next Steps (keeper of the dream)

Goals:

What our family including my (our) sibling with a disability wants for the future:

Next Steps:

Specify the actions you should take to achieve the goal(s).

1.

2.

3.

4.

5.

Goal(s) to Achieve in the Next Three Months

Families, including their relative with a disability, are to take the goals they have established in this document and prioritize them in order of importance. Pick the top priority to work on in the next three months:

Goal Priority 1: _____

_____

Goal Priority 2: _____

_____

Goal Priority 3: _____

_____

Goal Priority 4: _____

_____

Goal Priority 5: _____

Other information that you would like to add about your sibling:

ONE MORE THING – Individuals with disabilities are more likely to show signs of dementia at earlier ages than others, but often aren't assessed due to their cognitive abilities. This makes it important to assess their abilities early in adulthood to establish a baseline that may be helpful later in life if caregivers or family members detect early signs of dementia.

More information about the connection between dementia, Alzheimers and people with developmental disabilities at http://www.mindandmemory.org/

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

NTG-EDSD

v.1/2013.2

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

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(1) File #: _____ (2) Date: _____

Name of person: (3) First_____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

(10) General characterization of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(11) Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(12) Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(13) Conditions present (*check all that apply*)

	Vision impairment
	Blind (very limited or no vision)
	Vision corrected by glasses
	Hearing impairment
	Deaf (very limited or no hearing)
	Hearing corrected by hearing aids
	Mobility impairment
	Not mobile – uses wheelchair
	Not mobile – is moved about in wheelchair

(14) Significant recent [in past year] life event (*check all that apply*)

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

(15) Seizures

	Recent onset seizures
	Long term occurrence of seizures
	Seizures in childhood, not occurring in adulthood
	No history of seizures

If MCI or dementia is documented complete 16, 17, &18

(16) **Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:

[ ] No

[ ] Yes, MCI

Date of Dx:

[ ] Yes, dementia

Date of Dx:

Type of dementia:

Diagnosed by:
- ◻ Geriatrician
- ◻ Neurologist
- ◻ Physician
- ◻ Psychiatrist
- ◻ Psychologist
- ◻ Other:

(17) Reported date of onset of MCI/dementia
[When suspicion of dementia first arose]
Note approximate year and month:

(18) Comments / explanations about dementia suspicions:

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[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
[19]**Activities of Daily Living**				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
[20]**Language & Communication**				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
[21]**Sleep-Wake Change Patterns**				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
[22]**Ambulation**				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

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	Always been the case	Always but worse	New symptom in past year	Does not apply
[23] **Memory**				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
[24] **Behavior and Affect**				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
[25] **Adult's Self-reported Problems**				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
[26] **Notable Significant Changes Observed by Others**				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

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[Check column option as appropriate]

	[27]Chronic Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	Bone, Joint and Muscle				
1	Arthritis				
2	Osteoporosis				
	Heart and Circulation				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	Hormonal				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	Lungs/breathing				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	Mental health				
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	Pain / Discomfort				
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	Sensory				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	Other				
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

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(28) **Current Medications**

Yes	No	Indicate type
☐	☐	Treatment of chronic conditions
☐	☐	Treatment of mental health disorders or behavior problems
☐	☐	Treatment of pain

For reviews, attach list of current medications, dosage, and when prescribed

☐ List is attached for reviews

(29) **Comments related to other notable changes or concerns:**

(30) **Next Steps / Recommendations**

☐ Refer to treating physician for assessment

☐ Review internally by clinical personnel

☐ Include in annual review / annual wellness visit

☐ Repeat in _____ months

Form completion information

(31) Date completed	(32) Organization / Agency
Name of person completing form	
Relationship to individual (staff, relative, assessor, etc.)	
Date(s) form previously completed	

Acknowledgement: Derived from the DSQIID (*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

Date we will review/revise this Letter of Intent: _____

Where it will be stored: _____