

Aging as a Parent of an Adult Child with Intellectual/Developmental Disability

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Agenda

Introductions

About The Arc of
King County

Developmental
Disability and
Aging – The issues!

Questions to ask
parents

Tracie and Paul's
Story

Items that go into
a 'future plan'

Grief and Loss

My Work with The Arc of King County

Senior Families

Seniors with Disabilities

Plans for Loved One's Future When
Parent/Main Caregiver is No Longer Able

This Includes System Navigation

Making Sure the Next People Who Provide Care
Can Do So As Your Loved One Deserves



The Arc of King County

Our Goal:

To further the civil rights movement for all persons with intellectual and developmental disabilities to thrive as equal, valued, and active members of the community

We promote and protect the human and civil rights of people with intellectual and developmental disabilities, actively supporting their full inclusion so that they can live, learn, work, and play in the community – making the world a better place for us all.

The Arc of King County's Support Programs

Disability-related workshops, classes and presentations

Healthy Relationships

Housing Stability

Information and Family Support

Supported Living/Representative Payee

IEP Parent Partner Program

Silver Tsunami

Parent to Parent

Contact Us

- To contact The Arc of King County and Parent to Parent
- **English:** 206-829-7053 OR Ask@arcofkingcounty.org
- **Spanish:** 206-829-7030
OR Preguntas@arcofkingcounty.org
- **African American Support** (Khadijah Toms): 206-829-7036 OR KToms@arcofkingcounty.org
- **Korean** (email only): Jkim@arcofkingcounty.org

**It Happens
so Fast!**



WELCOME

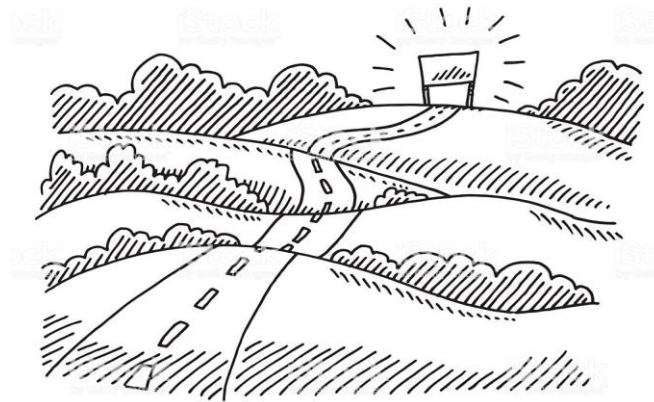
Goal:

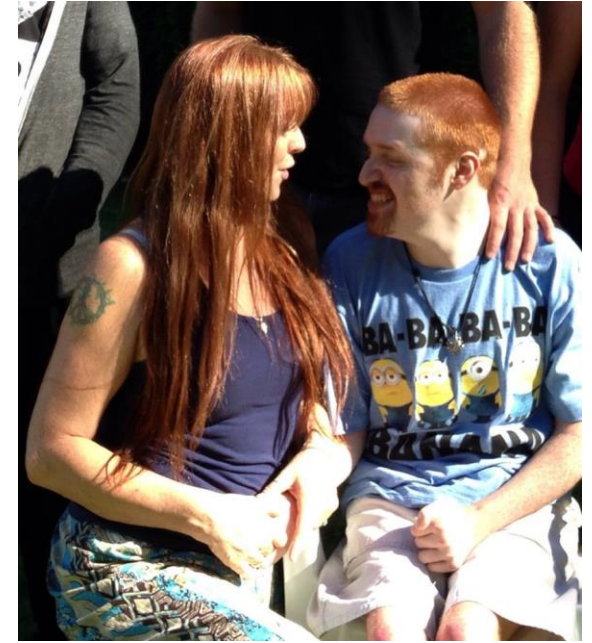
Provide questions you need to ask yourselves to help decide what is best for your own unique situation



Hope:

That you walk away with some ideas- and knowing we are here to help





MY REASON FOR FUTURE PLANNING

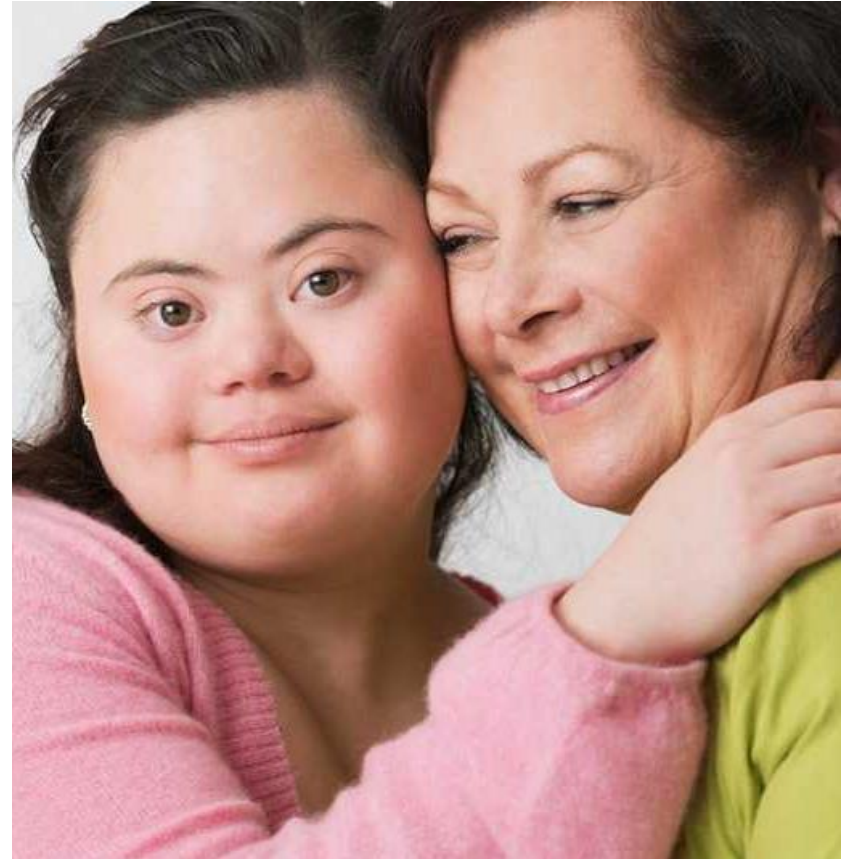


People with Disabilities into their Golden Years!

- Many people with I/DD and their caregivers spend their whole lives navigating the 'disability systems', but very few spend time putting a long-term plan together for the future.
- Sadly, we won't live forever – a long-term care plan is CRUCIAL for people with I/DD.
- Some people with I/DD may age into additional disabilities.
- Many people with I/DD are not adequately prepared for when they lose one or both of their parents (or caregivers).

Questions for Parents

- **Do you have a plan or a roadmap?**
- **What will their future look like without you?**
- **What do you want? What do they want?**
- **Where will they live?**
- **What are things do only you know, that you'll need to transfer to someone else?**
- **Do you have a Plan B?**





HOW TO BEGIN



- What will their future look like without you?
- Where will they live?
- Role of siblings
- Do you have a plan B?
- How ready are you right now?
- What will it take to begin a plan?
- What do they want?
- What do you want?
- Their life as a senior
- Limitations?
- Community supports?
- Plans for you
- What do you feel only you can do for your adult child?
- How will they handle grief?



IT IS HARD TO MAKE FUTURE-PLANS BECAUSE:

- Lack of information
- Difficulty addressing emotional issues related to caregiver's mortality
- Unavailable appropriate services
- Ability to afford services

AGING

There is little research on aging families with an adult with I/DD

There are not many studies available on recent shift to person centered care

An Improved quality of life has led to longer lives



FUTURE PLANNING

Planning for the Future

Why make future plans?

- To secure the loved one's place in their world and when parents/caregivers are no longer able to provide care or pass away.

What is involved

Financial- SSI, Trust

Supported decision making

Housing- In place, AFH, Assisted Living

Employment

Community Supports

Recreation, daily activities

Securing these things early on and why

I/DD AND DEMENTIA

Again- due to an increased quality of life for some people with I/DD lifespan has increased and so has the increased risk of dementia which can be similar to Alzheimer's



Specifically in people with Down Syndrome



Assessment is complex



No reliable cause, though best confirmation is in autopsy

I/DD AND DEMENTIA



- Symptoms that may be difficult in determining as symptoms due to possibility of already being baseline- typical for the person so may be hard to recognize
 - Loss of daily living skills
 - Difficulty retaining information
 - Seizures
 - Anxiety
- Anti-dementia medications
 - May be available but early diagnosis is key
 - In people with Down Syndrome dementia is typically not detected until in later stage
 - As a result, dementia may progress before diagnosis is made
- Dementia progress differs individually
- Services are limited for those with dementia, but there are services and support for those doing the care.

Services

- Arc of King County

<https://arcofkingcounty.org/resource-guide/agingseniors/overview.html>

- Personal Care and DDA
- Finding caregivers
- Guardianship/Supported decision making
- Social Security
- Long term planning
- Grief Support
- Housing

- Pathways-Sound Generations
- <https://soundgenerations.org/our-programs/>
 - **Food Security**
 - Meals on Wheels
 - Community Dining
 - **Transportation**
 - Hyde Shuttle
 - Volunteer Transportation
 - **Health & Wellness**
 - Fitness
 - Fall Prevention
 - Health Management
 - **Assistance Services**
 - Caregiver Support
 - Minor Home Repair
 - Medicare & Health Insurance
 - Legal Assistance
 - Crisis Prevention

Services

- ALTSA- Aging and Long-Term Support Administration

<https://www.dshs.wa.gov/altsa>

- Caregivers
- Housing
- Local services available
- In-home Care Services
- Long-Term Care Housing
- Medicaid
- Specialized Dementia Care Program

- Community Living Connections

<https://www.communitylivingconnections.org/>

- Individual consultation
- Options for long-term services and supports
- Respite care
- Care co-ordination
- Minor home repair
- Transportation
- State and federal benefits, including Medicaid



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IMPORTANT THINGS THAT CONTRIBUTE TO QUALITY OF LIFE WHILE AGING

- Maintaining social connections
- Building networks
- Stable environment to live in
- Engaging in day-to-day activities the person enjoys





A COUPLE THOUGHTS

- Many people with I/DD are not adequately prepared for when they lose one or both of their parents (or caregivers).
- Invisible Care
 - Although services may be difficult to access, the most difficult is finding not just care for a loved one, but those who care about them. This is just as important as the tangible items we need.
 - Focus should be on a meaningful aging experience

1. TOTALLY READY
2. GETTING THERE
3. WORKING ON IT
4. HAVEN'T STARTED
5. NOT A CLUE WHERE TO START

- Where are you in planning
- What you hope to leave with today





Letter of Intent

<https://acrobat.adobe.com/id/urn:aaid:sc:VA6C2:784096e2-146e-41af-ad01-bf38ed7571c5>

A QUICK WORD ON GRIEF AND LOSS

- It is normal for us to protect our loved one from pain, or something that may upset them, but no matter their level of understanding- it will be noticed when someone – or a pet is no longer around, the person will notice this and without somehow knowing that they will not return they are left to fill in the blanks and this can be more distressing than knowing the truth as they are able to understand

LINK TO EVALUATION:
WE LOVE TO KNOW
HOW WE ARE DOING!
WHAT WOULD YOU
LIKE TO SEE MORE
OF/LESS OF? WAS THIS
HELPFUL? HOW CAN
WE IMPROVE?
REMEMBER- THESE
EVENTS ARE FOR YOU,
AND WE WANT YOU
TO GET WHAT YOU
NEED OUT OF THEM.

■ **Link:**

■ https://www.tfaforms.com/4878995?tfa_186=70IQg00000OMQNq



THANK YOU

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