

# **CANADIAN CENTRE FOR ELDER LAW**

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# International Scan of Resources Supporting People with Disabilities to Participate in Decision-Making

#### **Summary of Decision-Making Resources**

#### **Existing Resources**

- Canada
  - o Most of the Canadian decision-making tools are from the community living sector.
  - o Information is geared towards planning for the future, setting goals, and daily living.
  - o These resources aim to help people gain independence as they move into adulthood.
- Australia
  - o Most Australian resources are also from the community living sector.
  - A few resources are for people living with dementia or in long-term care.
- United Kingdom
  - o UK resources are primarily geared towards children living with disabilities.

#### **Application to Future Tool Development**

• Decision-making tools do exist in Canada and other jurisdictions that can form the basis for creating decision-making tools aimed at supporting people living with cognitive impairments to participate in decision-making.

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- The existing tools will likely need to be adjusted as the goals would be different.
  - Most of the community living sector decision-making tools are geared toward helping youth living with disabilities that are
    moving into adulthood to learn independent living skills, plan for the future, and set goals for their life.
  - However, for those living with dementia and other cognitive impairments, the intention is to support their previously-developed planning and decision-making skills, and plan for future incapacity.
- The decision-making tools do make good use of imagery to explain concepts, but some of the graphics may need to be altered to be more suitable to the older adult population, as a great many feature cartoon imagery.

## **Canadian Resources: Community Living Sector**

Tool	Who Created	Who Is It For	Description
Self-Management British Columbia: Self-Management Programs <sup>1</sup>	Self-Management British Columbia	Persons with chronic conditions, family members, health professionals	Community Group self-management programs: small group workshops weekly for six weeks, teaching practical skills and information covering healthy eating, exercise, pain management, stress management, communicating with healthcare professionals, managing medications, and planning and problem solving.  Available in English, Punjabi, and Chinese; also, an Indigenous version of program. Program for cancer, chronic conditions, diabetes self-management, chronic pain. Self-Management Health Coach Program: telephone-based coaching to help become better self-managers, once a week for 30 minutes for three months
Addressing Personal Vulnerability Through Planning <sup>2</sup>	Community Living British Columbia	CLBC Staff, Service Providers, Self- advocates, Families, Friends	Guide to adding intentional safeguards into planning for adults with developmental disabilities.  Describes steps to safeguarding through planning including learning how to think about safety, applying safeguards to planning, learning how to balance risk-taking, and identifying, creating, and implementing safeguards to daily life.

<sup>&</sup>lt;sup>1</sup> "Self-Management Programs", online: *Self-Management British Columbia* <www.selfmanagementbc.ca/>.

<sup>&</sup>lt;sup>2</sup> "Addressing Personal Vulnerability Through Planning" (2011), online: *Community Living British Columbia* <www.communitylivingbc.ca/wp-content/uploads/2018/02/Addressing-Personal-Vulnerability-Through-Planning.pdf>.

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Belonging to One Another: Building Personal Support Networks <sup>3</sup>	Community Living British Columbia	Self-Advocates, Families, Service Providers, CLBC Staff, Community Members	Resource booklet on how to support friendships, make social connections, build support networks for adults with developmental disabilities.  Outlines the importance of promoting personal support networks, how personal supports can be safeguards, and how to help people with disabilities to develop these support networks.
Responding to Vulnerability	Community Living British Columbia	Self-Advocates, Families, Service Providers, Caregivers, Other Concerned People	Paper for discussion with people who have connections to people with developmental disabilities, to learn and talk about safeguards, way to respond to vulnerabilities. Discusses how everyone is vulnerable sometimes, but people with disabilities are more vulnerable, and safeguards help people manage their vulnerability themselves.
Rights & Safeguards: A Guide for Self- Advocates <sup>4</sup>	Community Living British Columbia	Self-Advocates	Video and print version.  For self-advocates, to enhance awareness of rights and way to be save in community Lists rights, lists what can do to address safety (physical, emotional, financial).  Includes right to take part in decisions made about you, control over spending.
Support Networks: A Guide for Self- Advocates <sup>5</sup>	Community Living British Columbia	Self-Advocates	For self-advocates, to guide process of building personal support network.  Discusses what a support network is, why it is important, how to meet people, how to connect with people.
Understanding Vulnerability: A Guide for Self- Advocates <sup>6</sup>	Community Living British Columbia	Self-Advocates	Tool for self-advocates, and family, CLBC staff, service providers, others about importance of being aware of vulnerabilities so intentional safeguards can be planned to address them.  Discusses what vulnerability means, why it's important to know about vulnerability, what safeguards are, how planning makes you less vulnerable, how you can reduce your risk (i.e., balancing too much and no risk).

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<sup>&</sup>lt;sup>3</sup> "Belonging to One Another: Building Personal Support Networks" (2009), online: *Community Living British Columbia* <www.communitylivingbc.ca/wpcontent/uploads/2018/02/Belonging-To-One-Another-final.pdf>.

<sup>&</sup>lt;sup>4</sup> "Rights & Safeguards: A Guide for Self-Advocates", online: *Community Living British Columbia* <www.communitylivingbc.ca/wp-content/uploads/2018/02/Rights-and-Safeguards1.pdf>.

<sup>&</sup>lt;sup>5</sup> "Support Networks: A Guide for Self-Advocates" (2010), online: *Community Living British Columbia* <www.communitylivingbc.ca/wp-content/uploads/2018/02/Support-Networks-A-Guide-for-Self-Advocates.pdf>.

<sup>&</sup>lt;sup>6</sup> "Understanding Vulnerability: A Guide for Self-Advocates" (2013), online: *Community Living British Columbia* <www.communitylivingbc.ca/wp-content/uploads/2018/02/CLBC-Vulnerability-Book.pdf>.

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I Can Be Safe Online <sup>7</sup>	Community Living British Columbia	People living with disabilities, Families, Friends	CLBC's online safety website, tool for people to learn how to be safe online while connecting with community.  Has videos, tips, links to other online safety resources.  Tips include how to protect passwords and privacy, how to set limits, how to be safe online, and how to post online safely and wisely.
CLBC Self Advocate Workbook: My Plan <sup>8</sup>	Community Living British Columbia	Self-Advocates	Guide for adults with developmental disabilities who want to take charge of planning.  Discusses what person-centered planning is, get to think about who you are, life, dreams, priorities, goals.  Helps plan out next steps to developing a plan and get support with planning.
Information for Families Sheets <sup>9</sup>	Community Living British Columbia	Families	These information sheets for families of people with disabilities outline the CLBC services which can help the person with disabilities making decisions.  Describe employment supports, Individualized Funding Program, and planning.
myBooklet BC <sup>10</sup>	Developed by Family Support Institute	People with Disabilities and Family	Online tool for families and people with disabilities to create information booklets for others to share information with teachers, therapists, friends, and family.  Booklets contains biographical info, describes self and interests, what is important to them, how to support self and be with them, skills and abilities, relationships, equipment, medical info, medical team, routines, learning plan, quality of life profile, list of vision, goals, and what have accomplished.
Disclosing Your Disability: A Legal Guide for People with Disabilities in BC <sup>11</sup>	Disability Alliance BC	People with disabilities	Guide is for people with disabilities, to inform and assist with planning and decision-making when considering disclosure to an employer.  Covers your legal rights and responsibilities, employer's responsibilities, deciding when/how to disclose, information about workplace accommodations, value of knowing employer, and value of knowing your own skills.

<sup>&</sup>lt;sup>7</sup> "I Can Be Safe Online", online: *Community Living British Columbia* <ICanBeSafeOnline.com>.

<sup>&</sup>lt;sup>8</sup> "CLBC Self Advocate Workbook: My Plan" (2010), online: *Community Living British Columbia* <www.communitylivingbc.ca/wp-content/uploads/2018/04/Plain-Language-Planning-Workbook.pdf>.

<sup>&</sup>lt;sup>9</sup> "Information for Families Sheets", online: Community Living British Columbia <www.communitylivingbc.ca/resources/information-sheets/>.

 $<sup>^{\</sup>rm 10}$  "myBooklet BC", online: Family Support Institute <www.mybookletbc.com/>.

<sup>&</sup>lt;sup>11</sup> "Disclosing Your Disability: A Legal Guide for People with Disabilities in BC" (2016), online: Disability Alliance BC < disability alliancebc.org/disclosureguide/>.

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### **Canadian Resources: Other**

Tool	Who Created	Who Is It For	Description
Know Your Rights: A guide for people who rely on public space <sup>12</sup>	PIVOT Legal Society	People relying on public space	Explains legal rights in situations which people who rely on public space may encounter.  Has some tools for deciding what to do when interacting with police. Includes street stops, arrest and detention, in home, good Samaritan drug overdose act, seizure by police, private security guards, etc.
Guidelines for Recovery-Oriented Practice <sup>13</sup>	Mental Health Commission of Canada	PLW mental illness, practitioners, managers, administrators, policy-makers, decision-makers	A guideline for following a recovery-oriented practice when working with people who are living with a mental illness.  Foundational document which can be used to create tailored guidelines or tools.  Covers how to create a language of hope to develop best outcomes, how recovery is personal and autonomy and self-determination must be upheld, how to determine own path to well-being, and how to respond to diverse needs, including adapting practice across the lifespan, and working with Indigenous people.
It's Your Choice Personal Planning Tools <sup>14</sup>	Public Guardian and Trustee of British Columbia	Anyone	Outlines the personal planning tools to help make decisions: Enduring Power of Attorney, Representation Agreement, Advance Directive, and nominating a committee.
Dollars and Sense  – A guide for your money <sup>15</sup>	Public Guardian and Trustee of British Columbia	Youth	Guide to help people learn about how to manage their finances, budget, how to file income tax, banking, investing, credit cards, and contracts/big purchases.

<sup>&</sup>lt;sup>12</sup> "Know Your Rights: A guide for people who rely on public space" (18 July 2019), online: *PIVOT Legal Society* <www.pivotlegal.org/know-your-rights-handbook>.

<sup>&</sup>lt;sup>13</sup> Mental Health Commission of Canada, *Guidelines for Recovery-Oriented Practice* (Ottawa: Mental Health Commission of Canada, 2015), online: <a href="https://www.mentalhealthcommission.ca/English/initiatives/11869/guidelines-recovery-oriented-practice">www.mentalhealthcommission.ca/English/initiatives/11869/guidelines-recovery-oriented-practice</a>.

<sup>&</sup>lt;sup>14</sup> "It's Your Choice Personal Planning Tools" (2019), online: *Public Guardian and Trustee of British Columbia* <www.trustee.bc.ca/Documents/adult-guardianship/It's Your Choice-Personal Planning Tools.pdf>.

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Practical Tool for	American Bar	Lawyers	This tool helps a lawyer consider what is the least restrictive decision-making option
Lawyers: Steps in	Association		for a client who has reduced capacity.
Supported			Identifies a series of topics and questions for lawyer to consider while interviewing
Decision-Making <sup>16</sup>			clients.

# **Australian Resources: Community Living Sector**

Tool	Who Created	Who Is It For	Description
Supported Decision-Making in Victoria: A Guide for Families and Carers <sup>17</sup>	Office of the Public Advocate (Victoria, AU)	Families and carers	This is a guide for families and carers, outlining what supported decision-making is and the responsibilities of becoming a legally appointed decision-supporter in Victoria.  Includes a plain language section with pictographs for the person with disabilities to understand the guide and supported decision-making.
Supported Decision-making Guide <sup>18</sup>	Western Australia's Individualised Services	Family and friends who support decision making	This set of resources includes a guide book on supported decision-making (plain language and easy read versions), pictograph, template, and videos.  Outlines how to help support someone's decision-making.  Guide covers getting to know the person, what supported decision-making is, what good support is, and understanding how someone commutates.

<sup>&</sup>lt;sup>15</sup> "Dollars and Sense – A guide for your money" (2016), online: *Public Guardian and Trustee of British Columbia* <www.trustee.bc.ca/Documents/CYS/dollars-and-sense/Dollars%20and%20Sense.pdf>.

 $<sup>^{16}</sup>$  "PRACTICAL Tool for Lawyers: Steps in Supported Decision-Making" (2016), online: American Bar Association

 $<sup>&</sup>lt;\!www.americanbar.org/groups/law\_aging/resources/guardianship\_law\_practice/practical\_tool/\!>.$ 

<sup>&</sup>lt;sup>17</sup> "Supported Decision-Making in Victoria: A Guide for Families and Carers" (Nov 2017), online: Office of the Public Advocate (Victoria)

 $<sup>&</sup>lt;\!www.publicadvocate.vic.gov.au/our-services/publications-forms/supported-decision-making-1/447-guide-to-supported-decision-making>.$ 

<sup>&</sup>lt;sup>18</sup> "Supported Decision-making Guide", online: Western Australia's Individualised Services < waindividualisedservices.org.au/resources/supported-decision-making/>.

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Preparing to Plan: A guide to thinking about what you need to have the life you want <sup>19</sup>	Western Australia's Individualised Services	Person living with a disability	Guide on preparing to plan for life, and why. Includes 12 planning cards. Cards lay out questions to ask in each topic area to guide what areas of life the person would like to plan for. Topics are building your group of supporters, communication, who am I, home, safety, work, sports and recreation, sexuality and intimacy, spirituality, equipment and technology, equality, and your team.
Planning for a Good Life <sup>20</sup>	Government of Western Australia Western and Australia's Individualised Services	Person living with a disability	This booklet is a planning tool which identifies the different areas of life that a person may want to plan for, and gives space to write down what they are good at, what they have, what they need, and what they would like for the future.  Topics covered include personal attributes, support system, sports, housing, education, employment, communication, health, and decision-making.
Shannon's Story <sup>21</sup>	Government of Western Australia Western and Australia's Individualised Services	Aboriginal youth with disabilities	This guide is intended to help Aboriginal youth plan for the future, and be helpful when obtaining the National Disability Insurance Scheme.  This guide covers several topics, including considering where one comes from, who are the important people in one's life, what one's interests and strengths are, and setting goals for the short- and long-term.
Tips For Your NDIS Planning Meeting <sup>22</sup>	Western Australia's Individualised Services and Government of Western Australia	Individuals living with disabilities	This guide gives tips for people to prepare for their meeting with the National Disability Insurance Scheme planner.  Topics include how the meeting will take place, what supporters can accompany you, what documents are needed, the plans and goals one may want to have considered, what questions the planner will ask, options for NDIS management.

<sup>1</sup> 

<sup>&</sup>lt;sup>19</sup> Western Australia's Individualised Services, *Preparing to Plan: A guide to thinking about what you need to have the life you want*, 3rd ed (Western Australia's Individualised Services, May 2018), online: <waindividualisedservices.org.au/resources/planning-card-set/>.

<sup>&</sup>lt;sup>20</sup> Government of Western Australia & Western Australia's Individualised Services "Planning for a Good Life", online: *Western Australia's Individualised Services* <waindividualisedservices.org.au/wp-content/uploads/2019/10/Planning-Doc\_NoLines-Fillable-tagged.pdf>.

<sup>&</sup>lt;sup>21</sup> Government of Western Australia/ Western Australia's Individualised Services, "Shannon's Story", online: *Western Australia's Individualised Services* <waindividualisedservices.org.au/shannons-story/>.

<sup>&</sup>lt;sup>22</sup> Western Australia's Individualised Services/Government of Western Australia "Tips for your NDIS Planning Meeting", online: *Western Australia's Individualised Services* <waindividualisedservices.org.au/wp-content/uploads/2019/10/Tips-for-NDIS-Planning-Meeting-in-Easy-Read.pdf>.

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Booklet 2 – Planning <sup>23</sup>	Australia, National Disability Insurance Scheme	Individuals living with disabilities	This booklet was created by NDIS for individuals to think about their life and goals for the future in preparation for their NDIS planning meeting.  Topics include current support network, daily activities, community and government services, and short- and long-term goals.
Helping People Make Decisions <sup>24</sup>	New South Wales Public Guardian	People living with disabilities	This booklet describes the rights people with disabilities have to make their own decisions, what supported decision making is, and lists resources.
Supported Decision Making: Information for families and friends <sup>25</sup>	New South Wales Pubic Guardian	Families	This factsheet explains to families or friend what supported decision making is, what their role is, and the appointment of a substitute decision maker.
Supported Decision Making Practice Framework <sup>26</sup>	New South Wales Public Guardian	Health Care Practitioners	This factsheet gives best practices for supported decision making with a personcentred focus.
Training Guide: Introduction to Supported Decision Making <sup>27</sup>	New South Wales Government Department of Justice	Disability services staff	This training guide is for facilitators of a one day workshop for disability services staff to train them to ensure they are supporting decision making in their clients.  The workshop discusses what supported decision making is, the rights of all adults to make their own decisions, and strategies and communication techniques.

<sup>2</sup> 

<sup>&</sup>lt;sup>23</sup> "Booklet 2 – Planning", online: Australia, National Disability Insurance Scheme < www.ndis.gov.au/about-us/publications/booklets-and-factsheets>.

<sup>&</sup>lt;sup>24</sup> "Helping People Make Decisions" (2017), online: *New South Wales Public Guardian* <www.publicguardian.justice.nsw.gov.au/Documents/Publications%20%20Factsheets/SDM%20Helping%20People%20Make%20Decisions%20Easy%20Read.pdf>.

<sup>&</sup>lt;sup>25</sup> "Supported Decision Making: Information for families and friends" (2017), online: New South Wales Public Guardian

 $<sup>&</sup>lt;\!www.publicguardian.justice.nsw.gov.au/Documents/Publications\%20-\%20 Facts heets/SDM\%20 Information\%20 for\%20 families\%20 and \%20 friends.pdf>.$ 

<sup>&</sup>lt;sup>26</sup> "Supported Decision Making Practice Framework" (2017), online: New South Wales Public Guardian

 $<sup>&</sup>lt;\!www.publicguardian.justice.nsw.gov.au/Documents/Publications\%20-\%20 Factsheets/SDM\%20 Practice\%20 Framework.pdf>.$ 

<sup>&</sup>lt;sup>27</sup> New South Wales, Department of Justice "Training Guide: Introduction to Supported Decision Making" (Parramatta, NSW: 2017), online:

 $<sup>&</sup>lt; www.publicguardian.justice.nsw.gov.au/Documents/13805\%20 Public\%20 Guardian\_Training\%20 Guide\_FINAL\%20v2\%20 email.pdf>.$ 

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Supported Decision Making <sup>28</sup>	New South Wales Public Guardian	People supporting persons with disabilities	This factsheet gives tips on how one can help a person with a disability to communicate their wishes effectively so the individuals can make and communicate their decisions.
It's My Choice! A Guide for People with a Disability, their Family Carers, Friends and Advocates <sup>29</sup>	Inclusion Melbourne & RMIT University	People with disabilities, families, carers, advocates	This guide is intended to help a person with disabilities make choices about what is important, what their goals are, make choices about daily life, with the help of a carer, family, or advocate.  Topics include how to communicate feelings and choices, what choices are important to the individual, how to set up a planning meeting, how to find services and supports to reach one's goals, and human rights.

#### **Australian Resources: Older Adult Sector**

Tool	Who Created	Who Is It For	Description
Supported Decision-making in Aged Care <sup>30</sup>	Cognitive Decline Partnership Centre	Aged Care Policymakers	This guideline outlines best practices for developing aged care policies that uphold supported decision-making.  The report describes the four decision-making principles from the Australian Law Reform Commission report and gives a plan for how policies can be updated to reflect best practices in supported decision-making.  Principles include the right of all adults to make decisions, the right to support in decision-making, the right to have wills and preferences reflected in decision-making, and the importance of legal safeguards from abuse or undue influence.

<sup>&</sup>lt;sup>28</sup> "Supported Decision Making" (2017), online: *New South Wales Public Guardian* <www.publicguardian.justice.nsw.gov.au/Documents/Publications%20-%20Factsheets/SDM%20Communication%20Strategies.pdf>.

<sup>&</sup>lt;sup>29</sup> P Ramcharan et al., *It's My Choice! Toolkit*, (Melbourne: Inclusion Melbourne & RMIT University, 2013), online: *Inclusion Melbourne* <a href="https://www.inclusion.melbourne/wp-content/uploads/2013/06/lts\_My\_Choice\_Vol2\_web.pdf">www.inclusion.melbourne/wp-content/uploads/2013/06/lts\_My\_Choice\_Vol2\_web.pdf</a>.

<sup>&</sup>lt;sup>30</sup> C Sinclair, S Field, S & M Blake, *Supported decision-making in aged care: A policy development guideline for aged care providers in Australia*, 2nd ed (Sydney: Cognitive Decline Partnership Centre, 2018), online: *New South Wales Public Guardian* 

 $<sup>&</sup>lt;\!www.publicguardian.justice.nsw.gov.au/Documents/SDM\_PolicyGuidelines\_FA\_V2\_Digital.pdf>.$ 

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Supporting	Cognitive Decline	Persons living with	This booklet aims to help people with dementia and their carers use supported
Decision-making:	Partnership Centre	dementia, carers	decision-making.
A guide for			Covers what supported and substitute decision-making is, describes steps for optimal
people living			supported decision-making, outlines the legal framework for decision-making and
with dementia,			planning, and gives resources for incapacity planning and supported decision-making.
family members			
and carers <sup>31</sup>			

# **UK Resources: Youth/Child Sector**

Tool	Who Created	Who Is It For	Description
Decision Making Toolkit <sup>32</sup>	Council for Disabled Children (UK)	Those working with children/young people with disabilities	Booklet on how people to support children and youth to make decisions.  Outlines what decision-making is, the concept of best interests decision making, and questions to ask self in helping the young person to make decision.  Contains links to decision-making tools created for children.
Your Rights, Your Future Toolkit <sup>33</sup>	Council for Disabled Children	Practitioners working with children with disabilities	This is a training module on helping young people with disabilities make decisions.  Areas covered are education, health and care plans, decisions about after they turn 16, and making personal budgets.
Get Your Rights <sup>34</sup>	National Children's Bureau/Council for Disabled Children	Children/Youth with disabilities	Website that outlines the right to be involved in healthcare decision making.  Have info on website, videos, leaflet, and checklist.  Topics include using the HNS, being treated well, making decisions, your local area, and wellbeing and adulthood.

<sup>&</sup>lt;sup>31</sup> C Sinclair et al., *Supporting decision-making: A guide for people living with dementia, family members and carers* (Sydney: Cognitive Decline Partnership Centre, 2018), online: <cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM\_Handbook\_Online\_Consumers-ReducedSize.pdf>.

<sup>&</sup>lt;sup>32</sup> "Decision Making Toolkit" (Jan 2017), online: *Council for Disabled Children* <councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0>.

<sup>&</sup>lt;sup>33</sup> "Your Rights, Your Future Toolkit", online: *Council for Disabled Children* < councilfordisabledchildren.org.uk/making-ourselves-heard/resources/your-rights-your-future-toolkit>.

<sup>&</sup>lt;sup>34</sup> National Children's Bureau & Council for Disabled Children "Get Your Rights", online: <www.getyourrights.org/>.

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Making	Office of the Public	For people who have	This plain language guide explains the Mental Capacity Act, the rights a person with
Decisions: An	Guardian (UK)	reduced capacity of	reduced capacity has to make their own decisions, and gives example stories of
Easyread Guide <sup>35</sup>		any age	supported decision-making and planning for future capacity, including when not have
			family members to support them.

<sup>&</sup>lt;sup>35</sup> Office of the Public Guardian, *Making Decisions: An Easyread Guide*, 2nd ed (OPG605) (London: Office of the Public Guardian, 2007), online: *Council for Disabled Children* <councilfordisabledchildren.org.uk/help-resources/resources/making-decisions-easyread-guide>.