Report to the Social Services Appropriations Subcommittee
For the Coordinating Council for Persons with Disabilities (CCPD)

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Issues from the Subcommittee to be addressed by the Coordinating Council:

- *Where Individuals With Disabilities Receive Services and*
- *The Standardization and Coordination of Eligibility and Delivery of Services*

The Coordinating Council for People with Disabilities (CCPD) will provide overview information regarding coordination of eligibility and delivery of services and any recommendations for improvement.

Information to consider – Where Individuals with Disabilities Receive Services:

These are complex issues addressed to varying degrees by individuals with disabilities themselves, their families, and an array of state and federal agencies, public entities, and community-based organizations. Points to consider include:

- The uniqueness of each person living with a disability, the diverse nature of their families and support systems, and the full range of needs, capabilities, and resources, all impact where services may be provided:
  - From in-home, to within their community, to locations far from home (e.g. some travel across the state from rural communities to access medical services from specialists only located along the Wasatch Front).
  - From segregated settings to fully inclusive settings (e.g. workplace settings where only people with disabilities are employed to locations where the person may be the only employee with identified disabilities; from their own home - to group homes - to care facilities, etc.).
  - Some services are paid for by programs based on meeting eligibility criteria (e.g. special education in local districts and charter schools; Vocational Rehabilitation services leading to employment; DSPD related to Medicaid Waiver programs administered by the Division). Others are paid for privately by the individual or family when a program or funding source (e.g. insurance) doesn't meet the need or a source doesn't exist to fund what is necessary.
- One of the greatest challenges that remains is that there are many individuals across the spectrum of disabilities, and/or their families, who simply do not have access to services and supports. Reasons for this may include:
  - They do not meet the eligibility criteria (e.g. level of disability; impact of the disability on education, ability to work, etc.; income level; etc.);
  - Because of waiting lists or specific selection criteria for services; or
  - Because they simply don't know what is available and how to access the programs or services.

Please refer to the "Disability Safety Document" prepared by Stephen Jardine, Office of the Legislative Fiscal Analyst, July 2011. This document has not been updated since it was created. However, it gives a general overview of a range of services utilized by people with disabilities and their families and the types of agencies and organizations providing services that may to address their individualized needs. In addition, there are unmet needs that greatly impact the lives of people with disabilities and their families that are difficult to capture and quantify.

Information to consider – The Standardization and Coordination of Eligibility and Delivery of Services:

- We have not made much progress on the standardization of eligibility because each agency is subject to differing rules associated with authorizing federal and state legislation, with funding restricted to use in the program it is appropriated for, and often the agency's mission. In Utah, our agencies collaborate and coordinate well. The CCPD is unique in the country as a forum for information sharing, collaborative problem-solving, and a mechanism to facilitate coordination at every level - from the systems-level where services are designed and implemented - to the consumer-level where services are received.

- We have made progress in recent years in coordinating services across systems when a person with a disability is found to be eligible for services from multiple agencies. Often individuals are connected to other programs and services.
- We have made progress in offering service coordination, service brokering, case management, team collaboration, and/or care coordination within and across systems. With that said, families, advocates, and individuals themselves tell us this improvement brings its own unique set of challenges. Now we need help "coordinating the coordinators" across multiple systems accessed by many individuals!

An Example: "A Life Map"…

That reflects the complexity of life for a child with a significant disability as managed by his parents.

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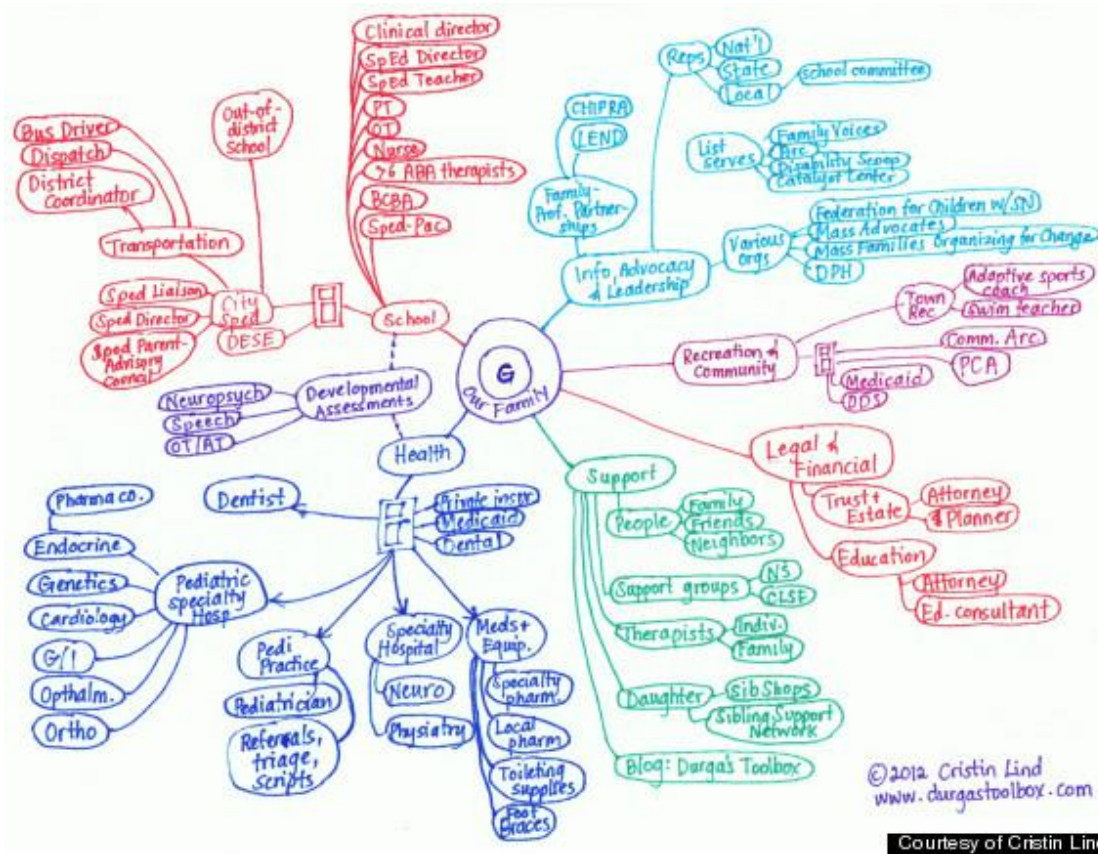
Recommendations:

- Essentially all individuals with disabilities and family members report the need for:
  - timely and reliable information and referrals (I&R),
  - connections, and
  - varying types and levels of support

  as their needs and priorities change over time. The CCPD is attending to how these needs are met and considering where improvements can be implemented within the agencies represented on the Council and where recommendations can be made to impact providers of I&R services in the community. The Council recognizes the challenge of the proliferation of information on the internet and determining effective strategies to assists people with disabilities and their families to access accurate, credible, evidence-based, information that helps and guides them to the services and supports they need.

- There continues to be concern about the security of computerized records and controlling access to sensitive information. Generally, families and individuals want ease of access and common eligibility, but also want assurance that information will not be shared without permission and only what is needed to address their immediate needs. Agencies represented on the CCPD adhere to strict confidentiality requirements while seeking the most appropriate ways to facilitate the coordination of services. The Council will continue to attend to these needs and interests.

- We recognize the challenge of computerized records systems that "don't talk to each other", even if an individual or family gives permission for the sharing of information (medical providers or state agencies as examples). The Council will continue to consider possibilities to resolve these concerns over time.

- Individual agency directors will continue to bring issues to the Council. The CCPD, as a state-level coordinating entity authorized by statute, will continue to bring issues to appropriate legislative committees as priorities warrant the collaborative attention of legislators.